

DOCUMENT RESUME

ED 418 526

EC 306 335

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TITLE The Transition to Adulthood among Adolescents Who Have Serious Emotional Disturbance.
INSTITUTION National Resource Center on Homelessness and Mental Illness, Delmar, NY.; Policy Research Associates, Delmar, NY.
SPONS AGENCY Substance Abuse and Mental Health Services Administration (DHHS/PHS), Rockville, MD. Center for Mental Health Services.
PUB DATE 1996-04-00
NOTE 100p.
PUB TYPE Information Analyses (070)
EDRS PRICE MF01/PC04 Plus Postage.
DESCRIPTORS Definitions; *Delivery Systems; Educational Policy; *Emotional Disturbances; Epidemiology; *Integrated Services; *Intervention; Models; Program Development; Secondary Education; *Severe Disabilities; Student Characteristics; Transitional Programs

ABSTRACT

This paper summarizes current knowledge on the transition to adulthood of youth with serious emotional disturbance in terms of epidemiology, effective interventions, and program models. The first section is introductory and provides definitions and characteristics of transitional youth noting special developmental tasks, outcomes for young adults, challenges to positive outcomes, and the special needs of homeless youth with serious emotional disturbance. The second section reports on ways in which the existing service systems (the child/adolescent system and the adult system) fail to meet the needs of these youth and the resulting poor outcomes. It urges establishment of a comprehensive and integrated system. Section 3 focuses on what works. It identifies transition service principles and essential service components and suggests ways to integrate systems and finance strategies. Section 4 looks at innovative approaches, including programs for transitional youth, adolescent programs, adult programs, and program evaluation and research. The final section offers specific recommendations for transition planning and for action. Five appendices provide: definitions of emotional disturbance, information on longitudinal data bases, summaries of conducive laws and policies, a listing of technical assistance/research and training centers, and a paper by Michelle Antholine: "The Transitional Community Treatment Team." (Contains approximately 180 references.) (DB)

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The Transition to Adulthood among Adolescents Who Have Serious Emotional Disturbance

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Under Contract to:
Child, Adolescent, and Family Branch
Homeless Programs Branch
Center for Mental Health Services
Substance Abuse and Mental Health Services Administration
U.S. Department of Health and Human Services
Rockville, MD

April 1996

EC-306335



ACKNOWLEDGMENTS

The Center for Mental Health Services (CMHS) gratefully acknowledges the many individuals whose hard work and expertise contributed to the completion of this report. Authors Maryann Davis, Ph.D., and Ann Vander Stoep, M.S., brought their own expertise in child and adolescent mental health services to bear on an extensive literature review. Maryann Davis is a clinical psychologist and assistant professor in the Department of Psychiatry at the University of Massachusetts. Ann Vander Stoep is a psychiatric epidemiologist and senior research investigator at Seattle Children's Home. The authors prepared an initial draft of this paper for a CMHS workshop on the needs of adolescents with serious emotional disturbance, and made subsequent revisions. Reviewers at the National Resource Center on Homelessness and Mental Illness, including Deborah Dennis, M.A., and Gail Hutchings, M.P.A., commented on each draft. Susan Milstrey Wells of Waterford, NY, edited the final text.

Finally, CMHS thanks the many policy makers, researchers, providers, advocates, family members, and youth themselves who are working tirelessly, and in many cases with inadequate and fragmented resources, to address the needs of this very vulnerable group. Their work is invaluable in helping to prepare adolescents with serious emotional disturbance for a successful transition to adulthood.

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PREFACE

I am pleased to present this paper, commissioned by the Child, Adolescent, and Family Branch, and the Homeless Programs Branch of the Center for Mental Health Services (CMHS). Youth who have serious emotional disturbance need ongoing support in their efforts to become independent, and yet they are often faced with the arbitrary loss of services when they reach the age of majority. Because they are also involved with multiple systems, they may fall through the cracks both within and between the child and adult service systems.

This paper is intended to provide a summary of our current knowledge concerning this population in terms of epidemiology, effective interventions, and program models. It will also serve as a technical assistance tool for those who are providing, or preparing to provide, services to these vulnerable youth.

The paper was informed, in part, by the rich discussion generated at the CMHS-sponsored workshop, "Adolescents with Serious Emotional Disturbance: Achieving Transitions/Preventing Homelessness" held in Arlington, VA in April, 1995. Workshop participants included researchers, clinicians, program administrators, family members, consumers, and representatives of national youth advocacy organizations and local, state, and federal governments. They came together to: (1) gain a clearer understanding of the barriers to successful transition to adult mental health systems for adolescents with serious emotional disturbance, (2) identify needed systems changes to eliminate these barriers, and (3) make recommendations to CMHS for next steps in addressing these issues.

Because multiple perspectives are needed to address the problems faced by transitional youth, the authors have attempted to bring together a broad range of information. I hope this paper opens a meaningful dialogue between different disciplines, and among policy makers, service providers, advocates, youth, and their families. The result of this effort will be much needed attention to a vulnerable group of youth.

Bernard S. Arons, M.D.
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EXECUTIVE SUMMARY

The plight of youth with serious emotional disturbance in transition to adulthood is grave. As a group, these youth are undereducated, underemployed, and have limited social supports. Drug and alcohol abuse are common, and suicide risk is high. These youngsters remain largely "unclaimed" -- falling through the cracks within and between the child and adult service systems.

Falling Through the Cracks

As with all adolescents, youth with serious emotional disturbance must master a number of significant developmental tasks to negotiate a successful passage to adulthood. Added to their difficulties is the need to make another important transition -- that from a system of children's services to the adult mental health and social service systems.

Both the child and adult service systems have failed to claim responsibility for helping children who have serious emotional disturbance make the transition to adulthood. This discontinuity of service is supported by strict eligibility criteria, rigid funding streams, and practices that do not recognize the needs of these youngsters.

The consequences of being set adrift are tragic. Without emotional maturity, social or independent living skills, or connections to community supports, youth with serious emotional disturbance are at risk of homelessness, dropping out of school, relying on public assistance, and increased rates of alcohol abuse and criminal activity.

The Need for a Comprehensive System

To help them make a successful transition to adulthood, youth with serious emotional disturbance need a broad array of supports. These include mental health and substance abuse treatment, case management, housing, education, vocational training, and employment.

Ideally, these supports should be community-based, comprehensive, and coordinated, requiring the collaborative efforts of providers within and between the child and adult systems. While case managers can be empowered to coordinate systems, system change is more efficient when the coordination is accomplished at the local or state level. System-driven approaches also reduce fragmentation and are more likely to endure beyond the temporary changes that case managers can make on behalf of their clients.

Agencies that work with transitional youth must focus on early identification of youngsters in need of assistance, and offer patient and persistent outreach to those who may be reluctant to accept help. Services should be offered in the least restrictive setting possible, be culturally appropriate, and be based on solid research. Families and youth must be involved in all aspects of service planning and delivery.

Testing Alternative Approaches

When existing services are better coordinated and financed, youth with serious emotional disturbance are less likely to be lost in the transition to adult services. In addition, the development of new and innovative services -- such as model programs that combine sophisticated psychiatric treatment with hands-on vocational training -- better serve those youngsters for whom existing approaches are not appropriate.

To determine the effectiveness of such efforts, evaluation is a critical component of program design. While much is known about the developmental needs of youth with serious emotional disturbance and the problems that preclude their smooth transition to adulthood, few studies have evaluated the success of innovative programs to determine how well youths' needs are being met. Additionally, policy makers and service providers need to know more about what types of supports are needed for specific groups of transitional youth at the age of emancipation -- including depressed youth, youth with family histories of abuse, youth from different cultural backgrounds, gang-involved youth, and young homeless pregnant women.

Recommendations for Action

All youth with serious emotional disturbance should be guaranteed the right to transition planning. Federal legislation should be enacted to guarantee appropriate transition planning and the provision of needed services for all youth with serious emotional disturbance who are aging out of children's services.

Federal funds for technical assistance, research, service demonstration and evaluation should be targeted for transitional youth to help guide the development of services. In addition, federal agencies such as the National Institute of Mental Health, the Substance Abuse and Mental Health Services Administration, the National Institute on Disability and Rehabilitation Research, and the Office of Special Education and Rehabilitation Services of the U.S. Department of Education, should model the needed interagency cooperation for transitional youth by coming together in their efforts to address the needs of this population.

Because transitional youth are involved in multiple service systems, states should establish a plan to address their needs through interagency planning councils and multidisciplinary activities. State and local agencies that serve transitional youth should

develop formal and informal mechanisms to exchange information and share resources to assist these youngsters.

A Good Beginning

Without appropriate programs and the necessary funding to support them, transitional youth suffer the frustration of trying to meet adult roles that they are developmentally unprepared to accept. The result is that the youth, and society at large, reap the consequences of increasing homelessness, crime, and dependency. The creative, fledgling efforts that are being made to address the needs of transitional youth in communities around the country are an excellent first step in solving these complex and challenging problems.

YOUTH IN TRANSITION TO ADULTHOOD

When Roxanne turned 18, she rode the bus two evenings a week to a local community college where she successfully completed her graduate equivalency diploma (GED). Living at home, she shared child care responsibilities for her newborn infant with her mother. Halfway through the year, Roxanne moved to an apartment with another friend who had a 2-year-old child. She worked nights cleaning office buildings, and her roommate worked days so they could share child care responsibilities. With the help of food stamps and a child health insurance plan, Roxanne was able to live independently, work, parent, and provide financial support for herself and her child.

When Rafael turned 18, he was kicked out of his home after an argument with his mother's boyfriend. Behind in his studies, he dropped out of the special education program in which he had participated for the past 3 years and found a job at a fast food restaurant in a central-city location. Because Rafael was not in school, he no longer qualified for a monthly psychiatric evaluation and medication review. When he got into a fight with a roommate and was arrested for assault and intoxication, Rafael lost his job. With no place to stay, no means of support, no treatment for his mental illness, and no connections to his family, teachers, or other social supports, he took up residence at a downtown emergency shelter.

Each culture recognizes a time of passage from childhood to adulthood. In our society, the beginning is marked by the onset of puberty, and the end is marked by acceptance of the responsibilities and privileges of early adulthood -- completing school, finding work, becoming sexually active, owning a car, voting and engaging in political activism, and contributing to the support of a household. These can be difficult tasks for any adolescent, but are especially challenging for youth with serious emotional disturbance.

This chapter defines the population of youth with serious emotional disturbance in transition to adulthood (referred to hereafter as "transitional youth"); examines the personal and social characteristics that make these youngsters especially vulnerable to poverty, disease, and homelessness; and discusses the important cognitive, psychological, and emotional passages they must negotiate to make the successful transition to adulthood.

A Definition of Transitional Youth

There is no uniform definition of youth in transition -- the population addressed in the literature varies in terms of specific age, disability, and service arena. An adequate definition must incorporate both the concepts of transition and of serious emotional disturbance.

Transition is used to refer both to a developmental period and to service eligibility. Developmentally, youth in transition are maturing from the period of adolescence to young adulthood. Broadly defined, this covers the ages of 14 to 25 years.

However, eligibility for many children's services ends at age 18. Because of this, most studies of transition emphasize the years just before and after the age of consensus (17 to 22 years of age). This paper will address the interface of the developmental transition and the service system transition, and will emphasize the outcomes seen after the age of maturity.

The term serious emotional disturbance has been a conundrum because attempts by various federal entities have lead to different "official" definitions (for a thorough discussion of this issue, see Bazelon Center for Mental Health Law, 1993). The Department of Education, the Administration on Developmental Disabilities, the Social Security Administration, and the Substance Abuse and Mental Health Services Administration have all developed definitions of serious emotional disturbance, each for its own purpose (see Appendix A).

For all but the Social Security Administration, the definitions are part of policies that act as guidelines to states. In reality, however, states can develop their own definitions of service eligibility that may or may not coincide with federal definitions (e.g., Davis et al., 1995a).

All federal definitions include the condition of a diagnosable mental illness that has lead to functional impairment in various important domains of life for children and adolescents. Thus, policies and laws that shape service systems are generally based on this framework. However, knowledge of this population is largely based on studies that may, or may not, have used an official definition. Some studies have used concrete conditions to select participants, such as having resided in a psychiatric treatment facility, assuming that this is likely to capture youth with serious emotional disturbance.

Taking all of these factors into consideration, this paper will use a broad definition of transitional youth as *those youth who, by virtue of maturation, policy, or law, are entering young adulthood, and who, by official or practical definitions, are considered to have had a*

serious emotional disturbance before the age of 18. In addition, because there are many adolescents with serious emotional disturbance who have never received services, they will be included, as much as possible, in the discussion of the transition process.¹

Characteristics of Transitional Youth

Much of the information on the characteristics of transitional youth comes from several major longitudinal studies that followed youth with serious emotional disturbance through the transition to adulthood. Four of these will be referred to extensively in this paper (see Table 1). For a more complete description of study participants and methodologies, see Appendix B.

TABLE 1
Characteristics of Longitudinal Studies of Adolescents
with Serious Emotional Disturbance

	NLTS	NACTS	YIT	McGraw
Number in Study	8,408 youth with disabilities	812 youth with serious emotional disturbance	209 youth with serious emotional disturbance	86 youth with serious emotional disturbance
Origin of Population	Students with disabilities from secondary schools	Half from community special education programs, half from residential mental health programs	Subsample of NACTS; half from special education, half from residential mental health	McGraw Center Psychiatric Residential Treatment Facility
Sites Sampled	303 school districts across the country	Six states	Six states	One facility
Age at Outset of Study	15 to 23 years	8 to 18 years	18 to 22 years	13 to 18 years
Length of Follow-up	3 years	6 years	point in time	5 years

¹ This paper will not address the service/policy issues and outcomes of individuals who experience their first serious symptoms of mental illness as young adults.

The National Longitudinal Transition Study of Special Education Students (NLTS) by the Stanford Research Institute is a study of more than 8,000 youth with disabilities, including those with serious emotional disturbance, who were in special education classes in 303 school districts across the country (Wagner, Blackorby & Hebbeler, 1993; Wagner, et al., 1992; Marder, 1992; Valdes, Williamson & Wagner, 1990).

The National Adolescent and Child Treatment Study (NACTS), conducted by the Research and Training Center for Children's Mental Health at the Florida Mental Health Institute, followed 812 youth with serious emotional disturbance in six states (Silver, et al., 1992; Prange et al., 1992; Greenbaum et al., 1991; Kutash et al., 1995). Half of the participants were from community special education programs, and half were from residential mental health programs. A subsample of 209 participants from the NACTS study was included in the Youth in Transition (YIT) study (Silver, 1993; Silver, 1995a; Silver, 1995b; Silver, Unger & Friedman, 1994).

Finally the McGraw Center Follow-up Study, conducted by the Research Department at Seattle Children's Home, examined the life course of 86 youth with serious emotional disturbance who were discharged from Washington State's first residential program for adolescents with serious psychiatric impairment (Vander Stoep, 1992). Subjects in the McGraw Study were in the highest range of impairment among youth with SED.

Prevalence. Because it is difficult to define the population of transitional youth, it is also hard to estimate the size of the population. The prevalence of psychopathology in children has been measured in two general ways. The first approach, used in studies falling under the rubric of psychiatry, involves estimation of the number of children who meet diagnostic criteria for specific mental disorders. The prevalence of diagnosable mental illnesses in children has been estimated between 17-22% (Costello, 1989). Point prevalence estimates for older adolescents are even higher (Reinherz et al., 1993; McGee et al., 1990).

The other approach, used in studies falling under the rubric of services research, applies both diagnostic and functional impairment criteria to populations of children to determine the prevalence of serious emotional disturbance. The prevalence of SED among children and adolescents has been estimated at 3-7% (Bird et al., 1988; Brandenburg, Friedman and Silver, 1990; Tuma, 1989). In a statewide survey of children in Washington, Trupin et al. (1988) found that point prevalence estimates of SED were higher for 9-12th graders (8.0%) than for younger school-aged children.

The population of interest in this paper are older adolescents who have Serious Emotional Disturbance. Applying the 3-8.7% estimates of SED to the general population of 14 million 18-21 year olds (U.S. Bureau of Census, 1994), there were between .4 and 1.2 million transition-aged youth with SED living in the United States in 1995. An estimated 150,000 delinquent youth with SED are detained by the juvenile justice system each year (OJJDP, 1995; Trupin et al., 1988). There is tremendous overlap of system utilization among youth with serious emotional disturbance.

Gender. Epidemiological studies suggest that gender related differences in the actual prevalence of SED shifts from a greater prevalence among boys in children, to a preponderance of females for most conditions after age 15 (Canino et al., 1995; McGee et al., 1992; Trupin et al., 1988). Eme (1979) has suggested that the greater prevalence of disorders among boys is related to a combination of biological and environmental factors; physical immaturity, more strictures on socially acceptable behavior, and a biologically based higher activity level.

However, the degree to which males are disproportionately represented among adolescents with SED is likely related to the nature of the expression of emotional disturbance in boys and girls, with boys being more likely to have obvious behavioral symptoms and girls more likely to have less obvious affective symptoms (Schwartz, 1992; Costello, 1989). Thus, boys may be overidentified, particularly in school settings, while girls may be underidentified. Regardless of the reasons, more boys than girls have received the attention of mental health and special education services.

Ethnicity. Ethnic groups differ in their prevalence of serious emotional disturbance and in their use of mental health services. In the U.S., Native Americans and African Americans show the highest prevalence rates of serious emotional disturbance. Asian Americans have a low rate of use of mental health services relative to their proportion in the general population (Hoberman, 1992; Meinhardt & Vega, 1987; Trupin et al., 1988). Assessed need for mental health services for Native Americans, at 15%, is nearly double that of the general population (Meinhardt & Vega, 1987). Though African Americans are 16% of the general classroom population, they are reported to represent one quarter of classroom students identified with serious emotional disturbance (Office of Civil Rights, 1993; Valdes, Williamson & Wagner, 1990).

Further, research shows that Native American youth with serious emotional disturbance are more likely to go without any treatment than children in other ethnic groups (Berlin, 1983), and that African American youth with serious emotional disturbance are more apt to end up in the juvenile justice system than in a mental health setting (Cohen et al., 1990; Comer and Hill, 1985; Vander Stoep et al., 1995; Snowden & Chung, 1990).

There has been insufficient research to determine whether differences in the diagnostic and service utilization patterns among ethnic groups of youth are due to actual differences in prevalence and incidence rates of mental illnesses, or to disease labeling patterns of mental health practitioners, cultural differences in the way symptoms are manifested or reported, or cultural differences in help-seeking behavior.

Socioeconomic status. Transitional youth disproportionately come from households with low socioeconomic status. Twenty-seven percent of households of the youth in the NACTS were below poverty guidelines, and 38-42% of the households of the youth in the NLTS had annual incomes under \$12,000, compared to the national rate of 15% of households

below poverty level. Derived annual incomes for youth in the YIT and NLTS were between \$8,000 and \$12,000 dollars.

In addition, high proportions of youth with serious emotional disturbance are from single-parent households, including 40% of the NACTS population and 44% of the NLTS population, compared to 24% nationally. Fewer than half of the biological mothers in the NACTS study, and 56% of the heads of household in the NLTS study, completed high school or received a GED, while 70% of the general population has graduated from high school (Annie E. Casey Foundation, 1994).

While many young people rely on some form of financial support from their families to help them become self-sufficient, transitional youth are less likely to receive this assistance. Circumstances such as the limited availability of need-based loans for vocational or job training programs, the requirement of a deposit for an apartment, and the need for a car for transportation to many jobs necessitate such support. Without it, many transitional youth remain in the lower rungs of the socioeconomic ladder.

Clinical characteristics. Few studies have examined current diagnoses among transitional youth. Diagnoses for the NACTS study were determined by diagnostic interview at the beginning of the study, when participants were 8 to 18 years old, and again during the final interview 7 years later.

As Table 2 shows, youth with serious emotional disturbance ages 8 to 18 were most commonly diagnosed with conduct disorders, followed by anxiety, depressive, and attention deficit disorders. Schizophrenic disorders were uncommon (Silver et al., 1992). Twenty-two percent of the NACTS population had substance use disorders (Greenbaum et al., 1991).

Data from the sixth annual follow-up of the NACTS population have recently been analyzed, allowing for more accurate estimates of the prevalence of mental disorders in transitional youth (Paul Greenbaum, personal communication, March 21, 1995). It must be kept in mind that the recent diagnoses were based on the Diagnostic Interview Schedule (DIS) for DSM-III-R, and the first-year diagnoses were based on the DIS for DSM-III. Thus, some differences in the distribution of diagnoses between the two age groups are due to changes in diagnostic systems. Additionally, some disorders, such as conduct disorder, do not have direct adult counterparts.

TABLE 2
Baseline Diagnoses of NACTS Youth with Serious Emotional Disturbance

DSM-III-R Diagnostic Group	NACTS Residential	NACTS Educational
Conduct disorder	77%	58%
Anxiety disorder	45%	37%
Depressive disorder	21%	17%
Attention deficit disorder	16%	8%
Schizophrenic disorder	5%	4%

Nonetheless, the findings are interesting, as shown in Table 3. The most common diagnosis among 17- to 25-year-olds was drug or alcohol disorders, followed by anxiety disorders and depressive disorders. Schizophrenic disorders remained infrequent. Among those youth who had a conduct disorder in year 1, 75% were diagnosed with a substance use disorder 6 years later, and one third of those who had reached age 18 were diagnosed with antisocial personality disorder. These findings are consistent with those of Robins (1978) who, in a longitudinal study, found that almost all individuals with antisocial personality disorder as adults had a conduct disturbance in childhood, and a third of youth with conduct disturbances as minors continued to have conduct disturbances as adults.

TABLE 3
Distribution of Diagnostic Categories among NACTS Transition-Aged Youth

DSM-III-R Diagnostic Group	NACTS 17- to <21-year-olds	NACTS 21- to 25-year-olds
Drug use disorder (drug/alcohol)	43%	49%
Marijuana use disorder	18%	22%
Alcohol use disorder	42%	43%
Anxiety disorder	34%	36%
Depressive disorder	10%	18%
Schizophrenic disorder	1%	2%

Dual diagnosis. In this paper, the term dual diagnosis applies to co-occurring mental health and substance use disorders. As can be seen in Table 3, it is common for transitional youth to have substance use problems. These data have not yet been analyzed to identify the extent of dual diagnosis, per se, however the prevalence of the diagnosis demonstrates conclusively the involvement that transitional youth have with drugs and alcohol. Earlier reports from the NACTS study showed high rates of dual diagnoses, from more than one third to one half, particularly when the degree of the co-occurring mental disorders were severe.

In a study of a community sample of youth with substance use, delinquency, and mental health problems, youth with serious emotional disorders had high rates of problem substance use (Menard & Huizinga, 1994). Substance use was even more problematic among youth with both serious delinquency and emotional problems. Youth with dual diagnoses have been found to have more suicidal behaviors, more crisis emergency room contacts, more private psychiatric hospitalizations, and more episodes where they acted out sexually (Evans, Dollard & McNulty, 1992).

A second type of dual diagnosis is that of serious emotional disturbance and developmental disorders. The NLTS study reports rates for developmental disorders among youth with serious emotional disturbance. Eight percent of participants were mentally retarded, nearly one quarter had a learning disability, and 13% had IQS below 71 (compared to 2% expected in the general population). Because many services that support youth in

transition have strict eligibility criteria, dual diagnoses can leave these youngsters suspended between service systems.

Negotiating the Transition to Adulthood

In order to graduate, work, and live independently from family, adolescents, including those with serious emotional disturbance, must complete the necessary developmental tasks of identity formation, personality/emotional development, cognitive development, moral development, socialization, and physical maturation. Each of these is described in brief below.

Identity formation. Establishing a sense of personal identity is a process that begins in infancy. As a child matures, he or she moves from dependency and impulsivity, through dependence upon external controls, to internalization of rules (Erikson, 1957; Loevinger, 1976; Marcia, 1980). Adolescents achieve a personal identity that allows them to distinguish their values and beliefs and to weigh impulses against these internalized controls.

Adolescents who have attained a sense of identity have less anxiety, less alienation from others, more respect for authority, more internal control, higher self-esteem, and greater success in school than youth who experience identity confusion. They are calm and nurturing toward peers and reflective in decision-making (Bernard & Clarizio, 1981).

Personality/emotional development. In personality and social development, the child progresses from the dependency, narcissism, and impulsivity of infancy to increasing independence, social awareness, and the ability for self-control and reality-testing in late adolescence.

Cognitive development. During normal development, a child makes the transition from concrete to formal operations. Typically the egocentrism of adolescence peaks at ages 12 to 14. The normal fantasizing and projecting that occur during this phase lay the groundwork for a growing competence to deal with abstract principles and concepts; to handle complex situations with flexibility, adaptability, and forethought; to see relationships between ideas and events; and to think in terms of probabilities (Piaget, 1977; Elkind, 1981).

Moral development. While a toddler makes ethical choices on the basis of simplistic, present-oriented concepts of right and wrong, the mature adolescent develops a set of complex, abstract principals that can be applied more universally (Kohlberg, 1968; Gilligan, 1982). Moral development involves a progression through stages of increasing ability to empathize (Hoffman, 1982).

Socialization. Throughout development -- from childhood, through adolescence, to young adulthood -- a child experiences growing independence and self-reliance, expanding peer relations, modifications of relationships with parents and home, and establishment of a network of social supports in a community.

Physical maturation. During puberty adolescents' bodies undergo tremendous changes and growth. The onset of puberty is much earlier today than in past centuries. In the 1850s, the average age of menarche was 16.5 years, while in 1990 this age had decreased to 12 years. Adolescents of the 1990s are sexually and physically ready to be adults long before they are psychologically and socially prepared.

During the years adolescents remain within the context of a supportive home environment, they gain the social, emotional, and independent living skills that allow them to catch up with their physical maturity. With appropriate family support and modeling, an 18-year-old will become capable of finding employment, forming close friendships, living in a semi-independent setting, shopping, cooking, driving, and balancing a checkbook.

Special Developmental Tasks of Transitional Youth

The age of emancipation is not the same as the process of emancipation. For young adults who have serious emotional disturbance, the disparity between role expectations and developmental status is often very wide. These young people must accomplish the same developmental goals as all adolescents, but they face particular problems in doing so. The very nature of their illnesses and circumstances often means they have to struggle to catch up emotionally, cognitively, socially, and vocationally before they are ready to assume adult roles.

Building new relationships with family. One of the most difficult tasks that all youth have in making the transition to adulthood is to achieve a balance between family support and independence. This is often a greater challenge for youth with serious emotional disturbance because of frequent and long-standing problems in family relationships.

As youth with serious emotional disturbance enter young adulthood, many are either overly distanced from, or enmeshed with, their families. Too great a distance results in premature independence, rejection of authority, and the inability to form trusting relationships. Enmeshment results in overdependence and lack of self-confidence. Either of these positions makes it difficult for transitional youth to achieve autonomy.

Transition is a difficult time for parents, as well, who feel both pulled and pushed by the child's alternating and sometimes coinciding needs for independence and support. For many youth with serious emotional disturbance, their family is the safety net that prevents homelessness and the advocate who helps to negotiate service systems. Those families that are able to play this critical role should be considered partners in the treatment process by the professionals and agencies that interact with transitional youth.

Cognitive and psychological milestones. Youth with serious emotional disturbance are often delayed in reaching key cognitive and psychological benchmarks. They are often

unable to control impulses or set goals, and have difficulty in establishing and maintaining relationships, and a reduced ability to foresee the consequences of their actions. Often, such difficulties result in depression and lowered self-esteem, as well as poor education and employment outcomes.

One of the most important psychological changes for this developmental stage is the emerging importance of the peer group (Feather, 1980; Lesser & Kandel, 1969). For transitional youth, reduced interpersonal skills can make peer interactions difficult. As a result, youth with serious emotional disturbance often make friends with peers who are also on the fringe of acceptance, leaving them without appropriate peer models. Transitional youth are also vulnerable to offers of token friendship in exchange for risk-taking behavior. Programs designed for transitional youth can use the importance of the peer group to shape *positive* behavior through such mechanisms as group therapy and peer job mentors.

Developing independent living skills. Independent living skills are particularly challenging for youth with serious emotional disturbance. Many of these skills are presumed to be taught by the family, while others are usually learned in school.

Those transitional youth who do not live at home or whose home life is highly disorganized are often without opportunities to learn such skills as cooking or balancing a checkbook. Since many youth with serious emotional disturbance do not complete their education, they do not acquire many school-based skills, such as vocational training. Their lack of education and employment skills makes it difficult to find a job.

Even beyond these considerations, gaining employment is challenging for transitional youth because of the nature of their disabilities. Many don't have the interpersonal skills, impulse control, or future orientation needed to maintain a job (for a thorough discussion of this topic, see Cook et al., 1994). Also, some youth may be ambivalent about giving up the role of patient or dependent child, or they may have unrealistic occupational goals. These concerns must be addressed in programs that seek to prepare transitional youth for employment.

Special tasks for homeless youth. Adolescents who have left untenable family situations adapt to street life with its familiar chaos, unpredictability, and violence. The longer a youth is on the streets, the more entrenched in street life he or she becomes. To obtain money, food, or a place to stay, homeless adolescents often resort to such extreme measures as panhandling, theft, drug sales, or prostitution.

Homeless youth, especially those who have had previous negative experiences with mental health treatment or other institutional programs (e.g., foster care, juvenile justice), may be particularly difficult to engage. Many street teens fear that if they contact service agencies, they risk being sent home or placed in custodial care. For these children to establish trust, the mental health and social service systems must approach them in a flexible, informal, and nonjudgmental manner and be willing to help them meet immediate survival needs (food, shelter, and clothing) prior to engaging them in further services (Robertson, 1995).

Those youth who are ready to leave the streets must find financial support and appropriate housing. Though difficult for all transitional youth, these tasks are particularly daunting for homeless adolescents. They typically have limited education and work experience. In addition, the nature of their illnesses and their experiences on the streets may leave them ill-suited to rules regarding sexual contact, alcohol and drugs, and participation in home maintenance imposed by some residential programs.

Program staff who work with homeless adolescents must respond to competing imperatives concerning the families of the youth they serve. Many programs proclaim family reunification as their ultimate goal, despite the profound erosion in the stability and structure of those families. Some experts feel that for a significant part of this population, reconciliation may be a more realistic goal, particularly for youth over the age of 16.

Outcomes for Young Adults

The success of transitional youth in completing the tasks of young adulthood are more understandable in the context of the success of their peers in the general population (Table 4). This picture of 'normal' development helps emphasize the condition of transitional youth described in subsequent sections. The majority of the general population at this age complete school, are employed, and live with others and family members.

TABLE 4
Status of Transition Aged Youth in the General Population

Status	Population	Percentage
Enrolled in College ¹	18-21 yr. olds	33%
Enrolled in High School	18-21 yr. olds	10%
Employed ²	20-24 yr. olds in school	56%
	20-24 yr. olds not in school	77%
Unemployed ³	20-24 yr. olds (1989)	13%
Residence ⁴		
Alone	20-24 yr. olds (1993)	6%
with Spouse	20-24 yr. olds (1993)	23%
with Relatives	20-24 yr. olds (1993)	56%
with Relatives	20-24 yr. olds (1970)	47%
with Non Relatives	20-24 yr. olds (1970)	16%
Sexually Active ⁵	18-19 yr. old women	75%

¹ U.S. Bureau of Census (1990).

² U.S. Department of Labor (1990).

³ U.S. Department of Labor (1990).

⁴ U.S. Bureau of Census (1994)

⁵ Forrest & Singh (1990).

School failure. Students with serious emotional disturbance are less likely to complete high school than any other group of students with disabilities. Of all students with serious emotional disturbance in the NLTS study who left school by the end of the 1986-87 school year, 40% had graduated, 56% had dropped out, and 3% had aged out (Wagner et al., 1992). The graduation and dropout rates for all students with disabilities were 58% and 35%, respectively (Wagner et al., 1992). Youth ages 15 to 20 in the general population had a graduation rate of 68%, and a dropout rate of 32% (Marder & D'Amico, 1992).

Both the NLTS and the NACTS studies found no marked differences in dropout rates between males and females, but they noted that African American students dropped out, or were expelled/suspended, at a higher rate than Caucasian students. In the NACTS six-year follow-up, nearly three quarters of Hispanic youth had dropped out.

Factors associated with high dropout rates among youth with serious emotional disturbance include:

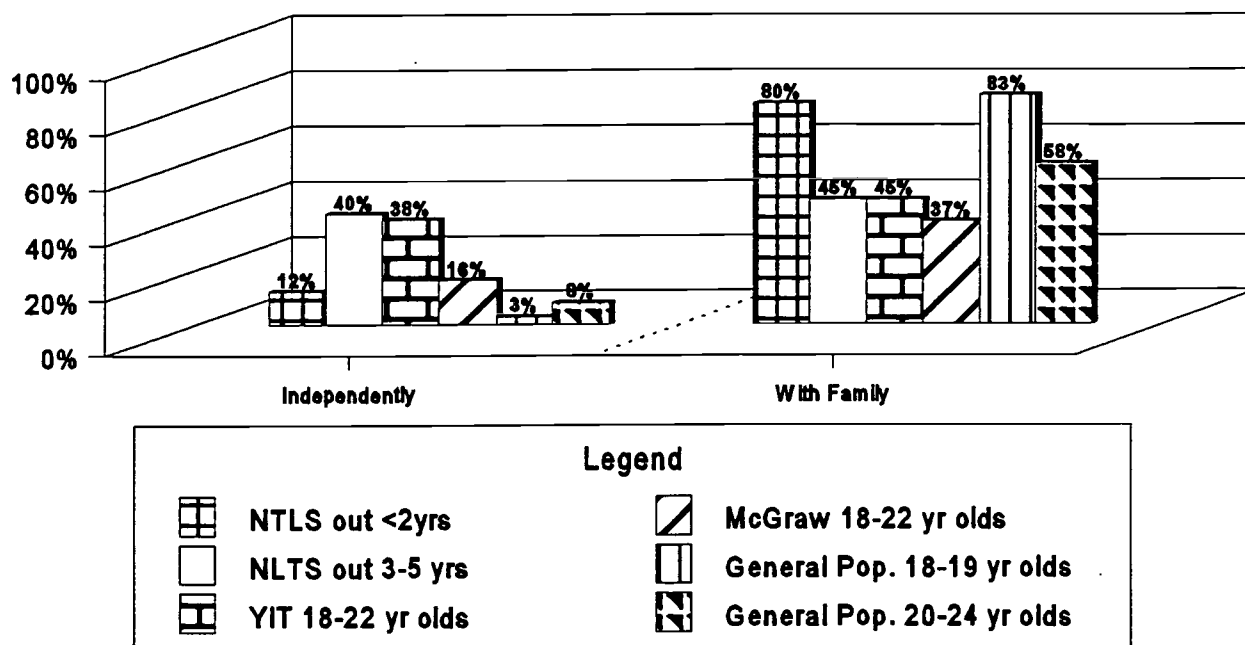
- boredom or dislike of school;
- behavioral problems, such as delinquent or aggressive behavior;
- school expulsion/suspension/truancy;
- getting married or having children;
- institutional changes, such as entering/exiting treatment programs, institutions, or correctional facilities; and
- low socioeconomic status, and family problems, such as alcohol/drug related problems.

As would be expected by the low proportion of graduates, few students with serious emotional disturbance go on to post-secondary education or training, and many of those who do are in vocational programs. It is important to keep in mind, however, that mental illness does not necessitate a decline in intellectual ability. With the appropriate support, youth with serious emotional disturbance are capable of attending college, and their right to do so is protected by the Americans with Disabilities Act (see Appendix C).

Unemployment. Given their educational history, high levels of unemployment among transitional youth are not surprising. A little more than half of the non-institutionalized youth from the YIT study were working or looking for work at the time they were interviewed, compared to 78% of all 20- to 24-year-olds who were working (U.S. Bureau of Census, 1992). Fifty-seven percent of those in the NLTS population who had been out of school for 1 to 2 years were unemployed.

Young men were more likely to be employed than young women in both the YIT and the NLTS studies, and fewer African Americans (45%) were employed than Caucasians (74%) in the NLTS group. Most employed youth from both the YIT and NLTS studies were working in competitive employment situations.

Figure 1
Residential Settings



Residential status. Transitional youth are more likely than youth without serious emotional disturbance to live on their own during young adulthood (see Figure 1). Students with serious emotional disturbance who had been out of school for less than 2 years were very similar in their residential status to the general population of 18- to 19-year-olds. However, students who had been out of school for 3 to 5 years, and youth from the YIT and McGraw studies, were far less likely than even 20- to 24-year-olds in the general population to be living with their families. These findings raise concerns that young adults with psychiatric disturbance, who are among the most vulnerable individuals, are also the least likely to reside with adults who might support them and advocate on their behalf.

Transitional youth are at high risk of homelessness. At 5 years after discharge from residential treatment, the McGraw Study found that nearly one third of the youth had at least one episode of homelessness since discharge. Among those youth who were ever homeless during the 5-year follow-up interval, the average number of homeless episodes was 1.6 per person.

Transitional youth who live with relatives have other issues, including learning independent living skills, negotiating relationships to gain more autonomy, and accepting greater responsibility for household maintenance and financial support. Parents who live with

transitional youth must learn how to facilitate their children's emancipation, adapt to the changing nature of their mental illnesses, and advocate for the young adult who must negotiate a new service system.

Criminal involvement. Given high rates of unemployment, minimal income, general lack of impulse control, and the prevalence of drug use among transitional youth, it is not surprising that they also experience an extremely high rate of criminal involvement. Forty-three percent of the NACTS six-year follow-up group, ages 14 to 26, had been arrested at some point in their lives, and 37% had been adjudicated delinquent or convicted of a crime. The most common reason for arrest reported by parents or youth in the NACTS study was property related offenses (60% of all arrests), followed by crimes against persons (37%), status offenses (34%), drug-related offenses (26%), and sex-related offenses (6%).

Youth in the NACTS study who were older, male, minority, or from a residential mental health setting were more likely to be incarcerated. In addition, having a baseline diagnosis of conduct disorder, and higher scores on externalizing behaviors, were positively associated with the risk of incarceration. High arrest rates among transitional youth may be related to the persistence of conduct disorder and the emergence of antisocial personality disorder among youth with conduct disturbance.

Additional Challenges to Positive Outcomes

Histories of abuse and neglect. Consistently high rates of abuse and neglect have been found among youth who enter mental health treatment programs. In one study of secondary school students with serious emotional disturbance, 60% had experienced abuse or neglect (Mattison, Morales & Bauer, 1991), while the records of 52% of youth in the NACTS study reported similar problems. More than half of a sample of adolescents receiving public mental health services ranging from home based family treatment to hospitalization in the Boston area were suspected of or confirmed as having been physically abused, and 41% had been sexually abused (Davis, unpublished data).

Within the child welfare, child protective, and foster care systems, an estimated 50% to 90% of children have serious emotional disturbance (Bryant et al., 1995; Trupin et al., 1993; Thompson & Fuhr, 1992; McIntyre & Keesler, 1986). Because abuse or neglect is one of the most common reasons that children enter these systems, the rates of such problems are especially high. In a group of 187 youth in custody of a state's social service agency, 85% to 96% had histories of abuse or neglect (Bryant et al., 1995).

Risks associated with sexual activity. Adolescents and young adults often believe they are immune from unwanted pregnancy and HIV/AIDS and other sexually transmitted diseases (STDs). The reduced social skills, social insecurity, and lack of impulse control among

transitional youth makes it unlikely that they will protect themselves. Transitional youth who have been sexually abused are at particular risk, since one of the common consequences of such abuse is frequent, impulsive, and unprotected sexual activity.

In the YTT study, 38% of young women and 19% of young men had children, and 10% of participants were expecting children. In a smaller study, nearly half of young women treated as adolescents in intensive residential treatment or psychiatric hospitalization had been pregnant between the ages of 17 and 20 (Vander Stoep, 1994). More than half of youth who were sexually active after being discharged from an adolescent psychiatric hospital program reported that they were practicing safe sex, however many of them reported the birth control pill as the mechanism of safe sex (Bonforte, Davis & Ziven, 1995).

While specific rates of STDs in transitional youth or adolescents with serious emotional disturbance are not available, it is clear that the behaviors that lead to unplanned pregnancy can also lead to infection. Substance abuse, which is common in this group, can lead to sexual relations with other substance abusers who are at higher risk of HIV infection. Among young adults on probation, those with mental illness were more likely to display high risk behavior for HIV than those who were not mentally ill (Pritchard et al., 1991-92). Furthermore, in samples of adults with serious mental illnesses, 7% to 20% of admissions to private and public mental health centers are reported to test positive for HIV antibodies (Sacks et al., 1992; National Institute of Mental Health, 1990). Thus, transitional youth must be considered at high risk for HIV infection.

Suicide. While estimates of suicide attempts or completions for transitional youth do not exist, the common precursors of suicide in this age group -- low self-esteem and relationship problems, and family discord (Contreras, 1981) -- suggest that suicide is a continuing risk for transitional youth.

For many youth with serious emotional disturbance, their entry into the child mental health system occurs through a suicide attempt or persistent suicidal ideation. Suicidal tendencies are among the most common reasons for treatment in emergency psychiatric settings (Hillard, Slomowitz & Levi, 1987), and are among the predictors of subsequent hospitalization. Comorbid depression and substance/alcohol abuse are common among adolescents and young adults who complete suicide (Carlson et al., 1991). The abuse that is prevalent in this population is also associated with suicide attempts in adolescents (Deykin, Alpert & McNamera, 1985; Stone, 1993).

Sexual orientation. Same-sex sexual orientation among transitional youth is likely to reflect the prevalence estimates of 10% to 13% for males and 7% to 10% for females reported across numerous ethnic groups (Remafedi & Blum, 1986; Kinsey et al., 1953; Martin, 1982; Gibson, 1989). The anti-gay messages expressed in society foster self-doubt and isolation

among many adolescents. Those youth with serious emotional disturbance are especially vulnerable, given their exposure to physical or sexual abuse, and the low self-esteem, poor interpersonal skills, and delayed development that are often characteristic of their illnesses.

Gay and lesbian youth are at extremely high risk of violence, depression, and suicide. In one study, 40% percent of gay and lesbian youth who sought social services had been victims of violent incidents, and 46% of those incidents were related to their sexual orientation (Hunter, 1990). Hetrick and Martin (1987) found that among gay clients who reported violence related to their sexual orientation, 49% were abused by family members.

Gay and lesbian youth are two to three times more likely to attempt suicide than straight youth, and they account for up to 30% of completed suicides among adolescents (Gibson, 1989). The majority of suicide attempts by gays and lesbians occur during adolescence.

Social isolation. Few studies have directly addressed social competence, skills, or support systems among transitional youth. However, several studies which have examined social competence in adolescents and children with serious emotional disturbance have found them, particularly those with conduct or behavior disorders, to have lower social competence (Thomlison, 1995; Schonert-Reich, 1993; Merrell et al., 1992; Janke & Lee, 1991; Asarnow, 1988; Richard & Didge, 1982). It is not likely that these deficits in social skills end upon entering young adulthood.

Both the NLTS and YIT studies yielded information about friendships, specifically numbers of friends and contact patterns. Eighty percent of the youth in the YIT study reported having two or more friends, and 38% of NACTS participants had contact with their friends two to five times a week. Older youth and those who had been out of school 1 to 2 years had fewer social contacts. However, none of the studies that have assessed friendships among transitional youth have looked at the quality of friendships or the types of friends transitional youth have.

Tenuous family ties. As young adults move towards greater independence from their families, they often continue to benefit from ongoing financial and emotional support. For many transitional youth, such assistance is diminished or unavailable.

As a group, transitional youth have experienced more separation from their family members due to death or divorce, protective custody arrangements, out-of-home treatment, or juvenile justice placements. Among adolescents in public mental health treatment in the greater Boston area, 65% had experienced separation from, or loss of, a parent (Davis, unpublished data).

Many parents of transitional youth have their own histories of mental illness, substance use, and incarceration. Additionally, families are challenged by the needs of adolescents with

serious emotional disturbance. Many of these youth are destructive of property, argumentative at home, frequently expelled or suspended from school, sexually active, and in and out of trouble with the law. Many adolescents with serious emotional disturbance run away from home. Compared to a normative sample, NACTS adolescents and their parents rated their families as low on the emotional bonding that family members feel toward one another (Prange et al., 1992). In some cases, families have been blamed for their children's behavior and are disregarded as partners in their treatment, which serves to further weaken already fragile family ties.

For those youth exiting the foster care system, ties to families are even more tenuous. Youth in foster care, particularly those with emotional disturbance, have received much of their care in group homes and have no identifiable families upon exit. Studies suggest that a quarter to a third of adolescents in foster care will neither return to their biological families nor be adopted (Lammert & Timberlake, 1986).

A Special Population: Homeless Youth with Serious Emotional Disturbance

"I would rather be homeless. It is cold and miserable on the streets, but it is better than being beaten up by parents who don't care." -- street teen (Seattle City Report)

Inadequate education and insufficient income, family separation, drug and alcohol use, and poor interpersonal skills leave transitional youth at risk for homelessness. Recent estimates indicate that there are approximately 1.5 million homeless adolescents in the U.S. (Rotheram-Borus, Koopman & Ehrhardt, 1991). Homeless transitional youth may have aged out of a system placement, such as foster care, with no follow-up plan or independent living skills. They may be runaway youth who have been living on the street for many years. They may come from families which are homeless.

Some have attempted to distinguish among "runaway," "street," and "homeless" youth based on notions of choice, access, and time away from home. In 1983, the U.S. Department of Health and Human Services offered the following definitions: *Runaways* are youth away from home at least overnight without a parent's or caretaker's permission; *homeless youth* are those with no parental, foster, or institutional home; *street kids* are youth who believe they belong on the street and have become accustomed to fending for themselves.

Homeless or street youth can be "throwaways" or "castaways," i.e., children who have been rejected, forced out, or abandoned by their parents. Teenagers who have left home by "choice" listed physical abuse, parental drug addiction or alcoholism, sexual abuse, and parents' emotional instability as reasons for running away. Youth who were forced out cited the family's lack of money or space, teenage pregnancy, and homosexuality as reasons (Robertson, 1992).

A vulnerable group. There are few longitudinal studies that differentiate youth with serious emotional disturbance who become homeless from those who do not. Studies that have compared poor, housed families to poor homeless families have noted that the similarities between the two groups is striking. What often pushes a family perched on the margins of subsistence into homelessness is a lack of social support (Stanford Center for the Study of Families, Children and Youth, 1991).

Many transitional youth have tenuous ties to family and poor support networks. They must often rely on their own skills, which are less well developed than those of their nondisabled peers. Youth who become homeless at a young age and spend long periods of time on the streets have a poorer chance of making a successful transition to life off the street (Boyer, Killpack & Fine, 1987).

As with youth who have serious emotional disturbance, minority and economically disadvantaged youth are overrepresented among homeless adolescents. The ratio of males to females is nearly 1:1 among homeless youth, whereas up to 75% of youth identified with serious emotional disturbance are male. There are more females in shelters and more males on the streets among homeless youth (New York State Council on Children and Families, 1984).

Homeless youth in transition. It is difficult to specify a particular subgroup of homeless youth as "in transition to adulthood" on the basis of age or other characteristics. Homeless youth, by definition, are functioning independently of adult supervision, and thus have been prematurely born into adult life. Because a primary developmental task of adolescence is to separate from the family and to establish independent existence, many young people who are homeless experience gaping discontinuities in healthy separation and other developmental processes.

Specific transitional issues arise when homeless youth who have been shelter residents or participants in programs for homeless adolescents no longer qualify for services. For these youth, as for other children with serious emotional disturbance, bridges must be built to adult services.

Prevalence of mental health problems. Homeless adolescents have been found to be at high risk for mental health problems. Often these problems stem from childhood histories of trauma and abuse. Less often, homeless adolescents have psychopathology similar to young adults with serious mental illnesses.

Morgan and colleagues (1995) administered the Youth Self Report to 186 homeless youth ages 13 to 20 who sought services from a Seattle agency for street youth. Relative to a normative population, higher proportions of homeless youth scored in the clinical and borderline ranges for most behavior subscales, especially delinquency, anxiety/depression, and self-destructive behavior. For the depression and attention deficit disorder subscales, the proportion of homeless youth in the clinical ranges was higher than clinical population norms.

Robertson (1990) found elevated prevalence across all mental health indicators for homeless youth compared to nonhomeless adolescents. Rates of DSM-III disorders, including psychotic symptoms, major depression, conduct disorder, and post-traumatic stress, were at least three times higher than those of a nonhomeless comparison group. Eleven percent of the group had a dual diagnosis of major depression and alcohol abuse.

By the time they reach the street, a majority of homeless youth have been hospitalized or have received outpatient treatment for psychiatric problems. Two thirds of a group of 113 homeless youth in Seattle were found to have had prior mental health treatment (Vander Stoep et al., 1993). Among homeless youth in Hollywood, nearly one quarter had received prior inpatient psychiatric treatment, and 23% had received professional help for mental and emotional distress (Mundy et al., 1990).

Summary

Youth who have serious emotional disturbance in transition to adulthood are a heterogeneous population. Despite their differences, however, these youth share a number of characteristics that place them at risk for homelessness, illness, poverty, and arrest.

Only about half of youth with serious emotional disturbance obtain a high school diploma or certificate. Failure to complete high school predisposes these youngsters to unemployment or underemployment, dependence on public systems, and long-term poverty. African American youth with serious emotional disturbance are particularly unlikely to gain employment.

Many transitional youth have tenuous ties to family and often enter adulthood without benefit of family support or advocacy. Their social networks appear to decline over time. Though the majority of transitional youth are sexually active, many do not understand or do not practice safe-sex. This leads to high pregnancy rates and increased risk for HIV infection and other sexually transmitted diseases.

Drug and alcohol abuse and conduct disorder are common psychiatric problems among transitional youth. Adolescents and young adults with serious emotional disturbance are at increased risk of suicide; gay and lesbian transitional youth are at particular risk for taking their own lives. The combination of lack of education, poverty, weak social supports, and the nature of their illnesses puts transitional youth at risk of arrest and of becoming homeless as young adults.

The personal and social deficits these youth must address makes their successful transition to adulthood especially problematic. Further, they must negotiate another important transition that is fraught with difficulties -- that from the children's to the adult service system. The challenges they face in doing so, and the problems that result when they fall through the cracks, are explored in the next chapter.

FALLING THROUGH THE CRACKS

"Even under the best of family circumstances, our current system cannot adequately support youth with serious emotional disturbance into adulthood."
-- Jane Walker, parent advocate

"The adult mental health programs I was assigned to were too impersonal and carried too many expectations I wasn't ready to fulfill." -- a 25-year-old woman with mental illness

As with all adolescents, transitional youth must master a number of significant developmental tasks to make a successful passage to adulthood. Added to their difficulties is the need to make another important transition -- that from a system of children's services to the adult mental health and social service systems.

Numerous barriers make this transition challenging and often unsuccessful. They include differing target populations, treatment philosophies, and funding streams for child and adult services; distinct and often dissimilar goals for youth in various children's services; and lack of coordination both within and between the systems of care for children with serious emotional disturbance and adults with serious mental illnesses.

The Child/Adolescent System

Generally, systems of care that serve children and adolescents target youth with serious emotional disturbance, though definitions of emotional disturbance may vary. The majority of youngsters who are served in these systems are diagnosed with conduct disorder or disruptive behavior disorders, and many also have substance use disorders. A number of states include youth in children's programs who are at risk for developing serious emotional disturbance. Only three states do not include any reference to serious emotional disturbance in describing the target population for children's services (Davis et al., 1995b).

The age of the target population also varies between agencies. Some, such as educational institutions, extend services to age 22, while others, including many states' child mental health systems, only serve youth to age 18.

Because of the broad array of their needs, many children and adolescents with serious emotional disturbance require comprehensive care that transcends agency and system boundaries. Yet Knitzer (1982) found that as many as two thirds of children with serious emotional disturbance do not receive needed services. Often these youngsters fall through the cracks between services agencies. Others receive redundant and sometimes overly restrictive care.

Since 1982 there has been considerable positive change in the philosophy, administration, and provision of services for children with serious emotional disturbance (Davis et al., 1995a; Knitzer, 1993; Behar & Munger, 1993; Stroul, 1993; Duchnowski & Friedman, 1990; Cole & Poe, 1993). The federal Child and Adolescent Service System Program (CASSP), established in 1984 and currently administered by the Center for Mental Health Services, set forth a comprehensive, coordinated model system of care for children and provided grants to states to help them develop services based on this model. CASSP promotes community-based, child-centered, and family-focused services offered in the least restrictive, clinically appropriate environment.

Typically, youth with serious emotional disturbance are served by public or private, nonprofit agencies in the following areas -- mental health, substance abuse, protective/foster care/adoptive services, education/special education, developmental disabilities, public health, social services, income assistance, vocational/rehabilitation services, juvenile justice, and housing. A number of these agencies provide mental health services to children, including those in the mental health, education, child welfare, and juvenile justice systems.

In recent years, the child and adolescent service system has become more creative and flexible, relying on interagency planning and case review, wrap-around financing, and alternatives to inpatient care to help maintain youth in their communities. Although progress has been made, there are still many barriers to creating a seamless system of care. Strict eligibility criteria, separate and limited funding streams, and different treatment philosophies among agencies that serve children and adolescents make it difficult to coordinate care for youth with serious emotional disturbance. In addition, most services are designed for children and younger adolescents and are inappropriate for transitional youth.

The Adult System

Adult mental health services are designed for people with serious mental illnesses, including disorders of thought, mood, perception, or memory that can grossly impair an individual's ability to function in major life areas (e.g., working, forming relationships, and caring for oneself). Generally, eligibility for adult services begins at the age when children's services end (e.g., age 19 in Massachusetts). Adult mental health systems often specifically exclude individuals with primary diagnoses of conduct problems or substance use disorders, except in psychiatric emergencies.

As with children and youth, adults with serious mental illnesses are best served by a comprehensive, coordinated system of care that meets their full range of needs, including mental health, social services, health, income assistance, recreation, vocational/rehabilitation services, and housing. However, in many cases, the focus of these services changes. For

example, adult services are often targeted for rehabilitation of skills and capacities that have been lost, as opposed to children's services, which are designed to establish such skills for the first time.

Additionally, adult mental health services are provided predominantly by the mental health system, with limited mental health services available through the justice system and vocational/rehabilitation programs. This makes the adult mental health system the primary provider of psychiatric services to transitional youth.

Since the mid-1970's, there has been a fundamental shift in the philosophy and delivery of services to adults with serious mental illnesses. The federal Community Support Program (CSP), established in 1977 and currently administered by the Center for Mental Health Services (CMHS), stimulated a long-term process of systems change that encourages the implementation of comprehensive community-based systems which are responsive to the needs of adults with psychiatric disabilities (Carling, 1984).

The CSP model recognizes that mental health treatment is not enough for many persons with serious mental illnesses, and that a community support system should include a comprehensive array of services such as client identification and outreach, case management, mental health treatment, housing, income maintenance, rehabilitation and medical care (Stroul, 1988). While many states and communities have developed community support systems and most have adopted the philosophy in principle, financial constraints have limited the capacities of other communities to establish all the components of a comprehensive service system or to serve the entire population (Levine, Lezak, & Goldman, 1986).

Falling Through the Cracks

There are many service cracks through which transitional youth can fall. Factors that complicate smooth transitions include lack of coordination between child and adult systems, inappropriateness of adult services for many young adults, and strict eligibility criteria for adult services that preclude young adults who were previously qualified for children's services. Though the assurance of a smooth transition to the adult service system has been identified as one of the guiding principals of a model system of care for emotionally disturbed children and youth (Stroul & Friedman, 1986), no states have reported significant progress in this area (Katz-Leavy, personal communication, December 1992).

Who is falling through the cracks? One of the problems in designing services for transitional youth is the lack of research that identifies which youngsters are likely to fall through the cracks between child and adult services. Much of the available information is circumstantial.

A recent study of treatment utilization patterns in a community-based sample found that older youth were underserved, even when holding other factors including diagnosis constant (Cohen & Hesselbart, 1993). Mental health service usage declined sharply at age 17 years.

Several reasons for this finding were examined. The underutilization was not explained by differential access to service, interest in obtaining service, or dual diagnosis. In fact 17-20 year olds were significantly more interested in receiving services than 10-16 year-olds (17% versus 10%).

The YIT study asked youth about the services they received and those that they desired. As can be seen in Table 5, many more youth wished to have help in certain areas, including career planning and counseling, than actually received such assistance. However, these data have not been analyzed to determine any differences between those who received and those who wanted services.

TABLE 5
Services Desired and Received by YIT Participants

<u>Services</u>	<u>Desired</u>	<u>Received</u>
Career planning	42 %	11 %
Job placement	35 %	13 %
Counseling	24 %	11 %
Substance abuse treatment	13 %	4 %
Case management	17 %	7 %

In examining the outcomes for 86 transitional youth discharged from a residential treatment center in Seattle, Vander Stoep (1992) found that by several measures of adjustment -- including residential stability, number and length of psychiatric hospitalizations, number of arrests and length of detainment, and use of crisis lines -- young adults had a more difficult time in their 19th year than they did either before or after this year. At 19, their participation in school and even employment dropped.

In particular, youth with thought disorders experienced more days of hospitalization and very little school or work involvement, while youth with affective disorders had more episodes of hospitalization interspersed with functional participation in work and school. Those youth who made significant gains during their stay in residential treatment were more likely to have completed school by age 19 (Vander Stoep, 1992).

Davis (1995) examined the differences between two groups of young adults who received intensive public-sector mental health services -- those who later received further services as adults and those who did not. Individuals with diagnoses of mood, anxiety, or

psychotic disorders as adolescents tended to receive services as adults, while those predominantly diagnosed with adjustment, conduct, or substance use disorders did not receive further care.

She also found that youth who had longer lengths of stay in adolescent programs and were discharged close to the age of emancipation were more likely to receive adult services. In addition, those who received adult services were older than those who did not, suggesting that with time, transitional youth are more likely to come to the attention of the adult system. However, these data do not address whether those who received adult services obtained appropriate care, or whether those who did not secure treatment needed it.

Who is at risk? A parallel question to who is falling through the cracks is who is most at risk. While neither of the larger longitudinal studies directly addressed this question, the YIT and McGraw studies (Vander Stoep, et al., 1993) examined outcomes for specific diagnostic subgroups, including participants with thought disorders such as schizophrenia, those with affective disorders, and those with conduct disorders. In both studies, youth with affective disorders were most successful in completing school and living in the community.

Overall, successful adjustment 3 years after discharge was related to attaining a high level of vocational training during adolescence, family support, participation in outpatient services during the first 6 months after discharge from residential treatment, and living in a community setting at 6 months post-discharge (Vander Stoep, 1994). Studies such as these can help to identify factors that are amenable to treatment and may lead to better outcomes, as well as identifying groups of individuals who are at particular risk if they fail to receive needed services.

Why Are They Falling Through the Cracks?

Eligibility. As the studies above suggest, there are several reasons why youth fall through the cracks of service systems. One common reason for an unsuccessful transition is the failure to meet eligibility criteria for adult services. The majority of youth in the child/adolescent system are diagnosed with conduct disorder or disruptive behavior disorders. The most common diagnosis among transitional youth is substance use disorder. Clearly, the target population definitions do not promote smooth transition from services in the child/adolescent system to the adult system.

Few studies have examined the issue of eligibility specifically. In King County, Seattle, in 1992, two thirds of the children admitted to mental health services at ages 17 and 18 would not have met diagnostic eligibility criteria within the adult mental health system (Vander Stoep, 1994). Youth who are not eligible for adult services often end up in the correctional system or on the streets, where they lack mental health supports and are vulnerable to mistreatment. Those youth who do meet the criteria for adult services may be assigned to

residential, vocational, or case management programs that are not appropriate for their age or developmental status, or that do not take into account the relative lack of severity of their mental health problems.

Coordination within and between systems. It is often a matter of chance which specific children's agency has primary responsibility for a given youth with serious emotional disturbance. Some youth end up in foster-care because their parents don't know how to handle their behavior and request voluntary services. Other children primarily express symptoms in school and are served in special education programs. Yet others are picked up in juvenile justice systems because of minor infractions associated with their mental health problems, particularly conduct disorders.

Each of these agencies has different transition goals for its clients. For children in child welfare, for example, the goal is independent living; for children in special education, the goal is employment; and for those in mental health services, the goal is a successful linkage with the adult mental health system.

None of these systems can or does take responsibility for facilitating transition in all aspects of life, and there is little coordination among them. Thus, while youth leaving foster care may get help finding housing, they are unlikely to be referred to the vocational training or mental health treatment programs that can help support them in their new environment.

In addition, success in making the transition to the adult system depends in large part on what kind of relationship the children's agency has with the adult service system. This varies widely. Coordination with the adult mental health system is often lacking in the child welfare, special education, and juvenile justice systems.

Youth who have been served in school systems may be at a particular disadvantage. Schools have, in many ways, been disconnected from other human service agencies, in part because they are locally run and financed. Also, the number of youth with serious emotional disturbance is a small portion of all students, even of all students with disabilities, thus it is difficult for schools to address their particular transitional needs.

Though federal law -- the Individuals with Disabilities Education Act or IDEA (see Appendix C) -- requires that students with serious emotional disturbance have a multiagency transitional plan with concrete goals for independent living, the law does not require service provision or follow-up monitoring. Also, IDEA does not address the needs of the many youth with serious emotional disturbance who drop out of school, or those who have lengthy stays in treatment and correctional facilities during late adolescence.

For those services that have both child and adult counterparts, such as mental health and criminal justice, the transition might appear to be easier. However, similar child and adult services often function independently of one another, with little communication or financing

strategies that promote coordination. In the mental health system, there is no state or federal mandate that requires special steps be taken for youth aging out of children's services. Further, many agencies do not have both child and adult components. Child welfare programs end at age 18, with provision of specific independent living services to age 21 if needed. Special education can extend to age 22, but has no adult counterpart. Housing programs generally provide housing for adults and for some emancipated minors.

Programs that do span age groups may be inappropriate for young adults with serious emotional disturbance. For example, vocational programs for young adults with disabilities are often geared to people who are developmentally or physically disabled. There are very few rehabilitation programs specifically for people with mental illnesses, and fewer still for transitional youth. The training programs and types of jobs that are appropriate for adults with diminished intelligence and short attention spans are often not desirable to young adults with average intelligence who have emotional disabilities.

Limited and/or fragmented resources. Fragmented, categorical, and limited funding is one of the greatest barriers to the provision of appropriate services for transitional youth. A complete review of the problems in financing comprehensive services for people with mental illnesses has been covered extensively in the literature (e.g., Cutler, Bigelow & McFarland, 1992; Dickey & Cohen, 1993; Friedman, 1992).

Some specific financial barriers to providing adequate services for transitional youth include the following:

- Certain benefits that help families with transitional youth, such as Aid to Families with Dependent Children, are discontinued when a child turns 18. Both youth with serious emotional disturbance and adults with serious mental illnesses may qualify for financial support through such programs as Supplemental Security Income, Medicaid, and food stamps, but the particular services they receive may be shaped more by the requirements of these programs than by their specific needs.
- Dollars do not follow individual youth; rather they often are attached to categorical services that neither address the specific needs of this group, nor are coordinated with one another to provide a comprehensive array of individualized services.
- Even when an adolescent has been in a system with flexible, wrap-around dollars, the services supported usually end when the recipient turns 18.
- Most adult mental health systems are hard pressed to adequately serve their target population with the limited resources allotted them.

Therefore, it is not feasible for them to simply open their doors to transitional youth.

- While much of the creative financing in mental health services has been focused on shifting dollars from inpatient to community-based care, a different strategy must be employed for transitional youth because they typically receive no care at all.

Systems such as corrections, public welfare, or substance abuse eventually bear the financial burden when the needs of older adolescents have not been addressed, and often have a very limited relationship with the agencies that serve transitional youth as minors. Thus, it is particularly problematic to shift dollars across the boundaries of systems where they are currently spent into systems where they could be spent preventively.

The special problems of rural youth. Transitional youth in rural areas face additional difficulties in acquiring services. Rural youth constitute nearly one third of all youth in the U.S. and have rates of mental disorders comparable to metropolitan youth. However, a number of factors hinder effectiveness of mental health service delivery in rural areas. These include underfunding of services, increased transportation and communication costs, inadequate support services, an overreliance on dwindling federal and state resources, difficulties recruiting and training specialists, and a rapidly escalating demand for services (Kelleher, Taylor & Rickert, 1992; Marty Hydecker, personal communication).

Even when services are available and adequate, rural youth may not get help because of the cultural stigma attached to mental illness and mental health services. In addition, rural communities may foster different expectations of educational and vocational attainment. Zibelman (1987) reported that rural 11th graders aspired to less prestigious occupations and anticipated completing fewer years of higher education than comparable urban youth. Though housing may be more affordable in rural areas, the range of opportunities for independent living is not as great. The challenges posed by service provision in rural settings necessitate such strategies as assertive outreach, coordination of community resources, and family support and assistance (Santos et al., 1993).

The Results of Falling Through the Cracks

The consequences of being set adrift are tragic. Lacking emotional maturity, social or independent living skills, or connections to community supports, youth with serious emotional disturbance are at risk of homelessness (Giles, 1991), poor school performance (Allen, Bonner & Greenan, 1988; Barth, 1986), intergenerational cycles of abuse and neglect (Ryan, et al., 1988), increased rates of alcohol abuse and criminal activity (Brown & Greenbaum,

unpublished manuscript), and high rates of unwanted pregnancies (Barth, Hacking & Ash, 1988). As Land (1990) writes, "The fact that adolescents face artificial and often inflexible discharge deadlines...places them at high risk for failure."

There is an emerging body of research that has determined that homeless adults were likely to be homeless when they were children (Simons & Whitbeck, 1991), and that disproportionate numbers of homeless adults experienced foster or other institutional placements as minors (Susser, Struening & Conover, 1987). Furthermore, childhood placements have been identified as a factor associated with long-term homelessness among homeless adults (Piliavin, Sosin & Westerfelt, 1989). There is also evidence that youth in out-of-home placements or institutional settings are at risk of becoming homeless when they leave. In the Hollywood study of homeless adolescents (Robertson, 1989), about one third of youth who had been in foster care, group homes, and juvenile detention spent their first night after discharge either on the streets or in a shelter.

The Need for a Comprehensive System

To date, service systems have failed to meet the developmental needs of young adults who are seriously impaired, but are not severely mentally ill. Such persons have the capacity for independent living, but need more guidance and support than individuals without emotional disabilities; and require more challenging employment options than developmentally disabled adults, but cannot readily become employed with mainstream vocational training. Often the young adult who has needs that cut across systems (e.g., mental illness, developmental disability, and substance abuse) is the worst off, as the various systems shift responsibility to one another for the individual's primary care. Principles to guide the development of a comprehensive service system for transitional youth and the essential elements of this system are outlined in the next chapter.

CROSSING TO SAFETY

"If they hadn't come and found me over and over again, I would never have left the street." -- homeless youth, 1988

In many ways transitional youth are in the same position that children and adolescents were 13 years ago (Knitzer, 1982). They are underserved, they are ineligible for many existing services, and services for which they are eligible are often inappropriate and fragmented. As a result, the unique developmental needs of transitional youth remain unrecognized and unmet. Families are often excluded from service involvement even when they continue to play a crucial role in their children's lives. These youngsters remain largely "unclaimed" -- falling through the cracks within and between the child and adult service systems.

What Works? Transition Service Principles

Many of the principles of an ideal system of care apply to individuals of all ages. It is not surprising, then, that principles to guide the development of services for transitional youth closely reflect those set forth for children and adolescents with serious emotional disturbance (Stroul & Friedman, 1986). However, any system for transitional youth must be designed to address their specific developmental needs. Characteristics of an ideal transitional system are described below.

A comprehensive service system. The needs of transitional youth cannot be handled by any one service agency. Instead, a *community-based system of care* is required, one that helps youth acquire the vocational, interpersonal, and self-care skills needed to become independent, contributing members of their community.

Services should be *comprehensive*, addressing the ongoing emotional, social, educational, recreational, vocational, and physical needs of transitional youth. They should also be *integrated and coordinated* such that the service system is seamless to the consumer. Child and adult service providers must coordinate their efforts with one another, drawing on the strengths of technologies developed by both systems. These include, for example, wrap-around services developed for children with serious emotional disturbance, and the supported housing and vocational training programs developed for adults with serious mental illnesses.

Care for all who need it. Because poor outcomes become apparent very early in young adulthood (e.g., when a youngster drops out of school), the needs of transitional youth should be *identified as soon as possible*. The treatment of any adolescent age 14 or older

should include a transitional plan. To reach youth who may have already fallen through the cracks, as well as those who have never come to the attention of any service system, programs for transitional youth should emphasize patient, persistent, and mobile *outreach*.

Services should be offered on *an unconditional basis* to all transition-aged youth with serious emotional disturbance. It is too easy for programs to screen out aggressive or difficult youth by rigid admission criteria. These behaviors are the very ones that lead to difficulty in the community, and should be the focus of treatment, rather than the basis for rejection.

Individualized treatment plans. Service efforts should be *skill- and goal-oriented* and must be *individualized* to address each youngster's unique set of strengths and needs. Transitional youth have to learn skills for independent living that help them address their social and interpersonal needs, their educational and work requirements, and their day-to-day experiences (Halpern, 1979). Service plans should be clear in the expectation that youth will move successfully from dependent child to more independent adult.

To ensure that services are appropriate and attractive, they should be offered in the *least restrictive, most normal, clinically appropriate setting* possible. Adolescents do not like to be set apart from their peers; many quit school because of the stigma of being in special classes. Transitional youth are more likely to continue in programs that are part of their communities and that have relevance to their daily lives.

Services for transitional youth should also be *culturally appropriate*. Needs differ for transitional youth from different ethnic backgrounds, and the availability of services varies between urban and rural communities. These differences should be identified and addressed in the service system. In particular, in-service training can help existing programs enhance cultural awareness, and ethnic community-based programs and agencies can be developed. Providers should be encouraged to employ appropriate role models for transitional youth.

A key role for youth and families. At all stages of treatment planning and delivery, transitional youth should be *empowered* to make decisions that affect their lives. Youth with serious emotional disturbance need to be treated in developmentally appropriate ways and may, at times, need to have their preferences overruled. However, their opinions should be respected, and they should be given safe opportunities to confront the consequences of their decisions.

Developmentally, the transition period is one that balances a youth's growing independence with the need for continued family support. Treatment and services should reflect *the appropriate involvement of family members* in all aspects of the transition process. Service systems should support the concept of a "lifetime family" -- a biological, adoptive, or foster family or community program that provides ongoing support to the individual in his or her efforts to function independently.

Parents have often been their youngster's most effective advocates, but may lose this role when their offspring reach legal age. Federal laws establish numerous rights for transitional youth, and *effective advocacy* can facilitate a youth's claim on these entitlements.

The need for research and program expertise. The system of care for transitional youth should be *based on solid research* and *guided by those with expertise* in the systems and issues involved. There are many questions that remain unanswered. Research will promote effective service delivery by enabling providers and policy makers to understand the fit between individual characteristics and appropriate programs. Current treatment models must be evaluated to determine their long-term impact.

There are several research and training centers that offer expertise in issues relating to youth with serious emotional disturbance, homeless youth with serious emotional disturbance, and psychiatric habilitation for young adults (see Appendix D). In addition, universities can play a major role in the cross-disciplinary training needed for professionals and students interested in working with transitional youth, especially those served in the public sector.

For example, the Department of Special Education at the University of South Florida offers a special graduate program in child and family policy, in collaboration with the Child and Family Studies Program at the Florida Mental Health Institute. This program combines state-of-the-art understanding of mental health service delivery, policy, and evaluation with similar knowledge about the education of children and adolescents with serious emotional disturbance.

Conferences and workshops can help educate the public about the needs of youth with serious emotional disturbance. Public support for child and adolescent mental health care has encouraged changes in this system, and can promote needed improvements for transitional youth.

Essential Service Components

To plan effective service delivery for transitional youth, providers and policy makers must consider the characteristics and needs of the individual, the environment in which he or she will function, and the specific services needed to support treatment goals (Modrcin, 1986). Ideally, these goals will include: (1) productive employment in the least restrictive setting that is feasible; (2) a comfortable living situation that is as normalized as possible; (3) community involvement, including adaptive day-to-day functioning, meaningful recreation, and the development of satisfying social relationships; and (4) cultural or ethnic integration. The essential ingredients of a system designed to promote these outcomes are outlined below.

Outreach. Transitional youth often are wary of formal helping systems. In addition, they may be too old to identify with children's agencies and too young to feel comfortable with

adult services. Successful methods of connecting with youth with serious emotional disturbance and homeless youth include street outreach, mobile vans, community organizing, public service announcements, telephone crisis lines, information fairs, posters, drop-in centers, peer counselors, teen theater, music and art groups, and outreach to schools, detention centers, public housing, and the police (Pires & Silber, 1991). To engage transitional youth of color, agencies and programs should be located in ethnic neighborhoods.

Mental health treatment. Young people with serious emotional disturbance may be so overwhelmed by various developmental tasks in childhood that they are unable to benefit from interventions that address underlying personality deficits. Often, ties to children's services are broken just when youth have established rapport with their caseworkers and are cognitively and emotionally mature enough to engage in serious psychotherapeutic work.

What would treatment for this population look like? As with homeless youth, traditional, appointment-based treatment settings are bound to fail (Vander Stoep & Blanchard, 1992). It may take many months of sporadic and unpredictable visits before a youth is comfortable enough with a therapist to disclose adequate information for an assessment. In a traditional setting, such a youth would be dropped from a caseload after a few "no shows." Treatment programs for transitional youth must be flexible enough to accommodate protracted testing phases.

To help reduce the stigma associated with mental health treatment, services should be provided in community-based settings. Like other adolescents, youth with serious emotional disturbance will be more likely to participate in programs that are structured enough to be safe and informal enough to be comfortable. Treatment should be focused on the developmental tasks that are specific to the transition process, including the skills needed to acquire and maintain food, shelter, and clothing. To address the needs of minority youth, services must be culturally appropriate.

Drug and alcohol treatment is sorely needed and too rarely provided to these youngsters. Because most adolescents who abuse substances do not recognize themselves as having problems or needing treatment (Robertson, 1989), outreach and education are vital. Substance abuse treatment may be paired with services that youth do value, such as food, shelter, clothing, or legal help in filing for emancipation. Since many shelters have strict policies against substance use, Robertson suggests that interventions for transitional youth who are homeless may be located in multipurpose drop-in centers that can house self-help meetings and educational programs.

Case management. Case managers often forge the link between child and adult systems for transitional youth, especially those who are homeless. As advocates, facilitators, and caring role models, case managers provide a source of consistent adult support for youth as a broader support network is being established.

Though case managers can be empowered to coordinate systems, creating system change is more efficient when the coordination is accomplished at the local or state level. System-driven approaches also reduce fragmentation and are more likely to endure beyond the temporary changes that case managers can make on behalf of their clients (Randolph, 1995; CMHS, 1994).

Housing. Appropriate housing is a critical and often unmet need for youth with serious emotional disturbance. A continuum of housing arrangements is needed, ranging from the most protective and structured to the most independent. These include emergency shelters, therapeutic residential programs, transitional housing (including supervised apartments, host homes, and apartments with live-in adult roommates), cooperative apartments, independent living with support services, and homeownership for young adults (Pires & Silber, 1991). A recent CASSP Technical Assistance Center publication describes these models and gives examples of programs that been implemented (Jarvis & Robertson, 1993).

Communities attempting to develop this kind of continuum encounter severe shortages of affordable housing in safe neighborhoods. Accessibility of needed services is also an issue. Generally, costs are highest and dangers are greatest in cities. Though the suburbs offer good educational and employment opportunities for youth, housing programs may encounter greater resistance from neighbors. Service providers may need to educate the community to help reduce stigma (Modrcin & Rutland, 1989). Rural areas, with a scarcity of resources, often pose the greatest challenge to community integration for youth with emotional disorders.

In creating community residential placement options for youth with serious emotional disturbance, the amount of structure and support should correspond to participants' level of functioning. The home environment should provide for the continued development of socialization, independent living, and work skills.

For youth who have the option of residing with their families during the transition years, in-home treatment foster care may be appropriate. In this model the training and support that is traditionally given to foster parents is given directly to the youth's parents. Thus, rather than teaching strangers how to care for and support troubled youth, the investment is made in the youth's own family.

An important component of this model is training for parents in the management of adult mental illness, advocacy, and preparation for emancipation. Respite care, 24-hour crisis intervention, and ongoing mental health case management may also be offered. Such a program may help families remain intact during this often difficult period.

For street youth, reacclimating to structured housing environments is a tremendous challenge. While youth are learning independent living skills in such programs, they may also be expected to abide by certain rules and regulations. Extension of unconditional support to young adults is necessary and, in many situations, impossible.

Education. Education is essential to the successful transition of youth with serious emotional disturbance, including those who are homeless. The high rate of school dropout among these youngsters argues strongly for alternative and street-based school programs that offer GED preparation. These programs create a nurturing environment for youth who may be behind in basic skills, and they provide practical advice about such issues as AIDS, drug abuse, legal rights, independent living, employment, and training opportunities.

Youth who want to return to school should be allowed to do so even if they lack a permanent address or are unable to produce transcripts or immunization records. The IDEA mandate that entitles special education participants over the age of 16 to transition planning should be enforced and extended to include children on the streets and in residential settings.

Programs that provide post-highschool support services to youth with mental illnesses while they attend colleges, universities, and technical schools have helped many students complete a higher education (Unger et al., 1991; Unger, 1993). Such programs include tutoring, reasonable accommodations, skills instruction, symptom management, peer counseling, personal support, and mental health treatment.

Vocational training. Though young adults with psychiatric disorders may have to alter their career aspirations, nearly all have the capacity for some personally fulfilling, productive activity. Vocational training is an important adjunct to mental health treatment, and should be tailored to meet both the specific developmental needs of the client and the available employment opportunities in the community (Modrcin, 1989).

Actual work experience is the most useful form of vocational training, although there are many issues that can be addressed effectively in a classroom setting, often in role-playing situations. These include managing stress in the workplace and developing social skills and appropriate workplace behaviors. Vocational training can expose youth with disabilities to a variety of job opportunities and help match them to a working environment according to their needs, abilities, and interests (Modrcin & Rutland, 1989).

The Thresholds Program in Chicago (Cook et al., 1994) provides several types of on-the-job training to transitional youth. The Fading Job Coach Model gradually reduces on-the-job support until the individual can work independently. Preventive support helps youth who are already working and have shown a need for assistance. For youth who wish to keep their disability confidential, staff address job-related problems away from the worksite. Thresholds uses a mobile unit to provide these specialized types of assistance.

Employment. Studies have shown that youth with serious emotional disturbance who are successfully employed during high school are more likely to have employment success in early adulthood (Vander Stoep & Taub, 1994; Unger, 1993). Schools are in the most appropriate position to begin teaching career planning and vocational skills during the

secondary years. Supervised employment in the community, both during the regular school year and during the summer, should be available as part of a comprehensive vocational education program (Unger, 1993).

It can be difficult to promote career aspirations among youth with behavioral disorders when the only available positions are minimum-wage jobs with no opportunities for training or promotion.

In a society where work is viewed as a means to increase purchasing power (Edgar, 1993), individuals may find they receive more income from illegal activities or from welfare benefits than from entry-level wages. In addition, they may risk losing paid medical benefits and other forms of public assistance by entering the workforce (Modrcin & Rutland, 1989).

Implementation of the Americans with Disabilities Act may help to decrease employer discrimination in hiring persons with emotional disorders; however, disincentives to paid employment must be revised. The ultimate challenge involves finding or developing social institutions that can provide meaningful alternatives to disenfranchised youth who do not benefit from available systems.

Advocacy training. Youth in transition have an advantage that children with serious emotional disturbance do not; they can advocate for themselves. Political and other forms of activism are a normal part of defining one's self-concept in this developmental stage; thus, transitional youth who learn to advocate for themselves are accomplishing an important task.

Local consumer advocates can extend themselves to this age group, or help transition groups get started. Additionally, families of transitional youth should continue to be involved as advocates for their young adult children. Community advocates should be identified and supported, as well. Though service systems can have an impact, what often makes the difference in a young person's life is a caring individual who opens his or her neighborhood, home, and heart.

Respite services. Many transitional youth live at home because there are no out-of-home placements or supported living arrangements for which they qualify. Any system of care should provide temporary respite for parents and other caregivers to help restore the energy and commitment needed to care for youth with serious emotional disturbance.

Recreation. For many transitional youth, lack of social skills interferes with their ability to choose and engage in developmentally appropriate recreational activities (e.g., dances, ski clubs, basketball teams). Community programs for youth with serious emotional disturbance can offer safe and supportive activities for clients, and can help youth acclimate to mainstream organizations and events.

Community nursing. Community nursing services are needed to address the particular health care issues of young adults, to act as a liaison to psychiatric professionals, and to offer a holistic perspective that integrates attention to physical and emotional health.

Crisis services. Often a mental health, family, or economic emergency in the life of a youth with serious emotional disturbance can lead to inappropriate arrest or hospitalization, or to homelessness. Transitional youth need access to crisis telephone lines and 24-hour crisis response services.

Evaluation. Programs that serve transitional youth should be evaluated to document and describe the services they provide and the impact these services have. To this end, consumers, clinicians, advocates, and researchers need to develop protocols to guide program development and clinical care. Measures used should be relevant to both consumers and program staff. Findings and descriptions of successful programs need to be disseminated widely to encourage their adaptation to local communities.

Putting the Pieces Together

Principles to guide the development of a system of care for transitional youth, and the essential service components are necessary, but not sufficient, ingredients to make the system work. As noted, a successful service system for transitional youth is comprehensive and coordinated, requiring the collaborative efforts of providers within and between the child and adult systems. This type of collaborative approach has been key to much of the success the child and adolescent system has experienced in recent years (Edgar & Siegel, 1992). Many of the suggestions below are based on Bruner's (1991) recommendations for collaborative efforts.

Identify barriers. To begin with, system planners must *identify and overcome barriers to service delivery*. These include differing eligibility criteria, treatment philosophies, and funding streams. Rather than being seen as complimentary, different treatment approaches often are seen as competing "best" models of care. Further, no single agency has the authority to compel cooperation or shared responsibility among all the parties involved.

Several authors have described innovative means to address these systemic issues (Boyd, 1992; Bruner, 1991). Bruner describes what he calls "a top-down strategy for bottom-up collaboration (1991)." In particular, he discusses the need for state-level interagency councils to establish the framework that leads to local-level collaboration. He believes that local demonstration projects can help illustrate effective strategies to reduce system fragmentation and to encourage the development of shared goals.

Plan at the state level. Unfortunately, transitional youth are not a high priority for states. When Koroloff (1990) reviewed state-level policies regarding transitional services for youth with serious emotional disturbance, she found that only 17 states had any policy at all,

and most required planning for youth with disabilities in general. Only one state -- Delaware -- established a separate program for youth making the transition from children's mental health services to adult mental health services.

All states currently have *state-level interagency planning councils* or boards. These groups can help address the needs of transitional youth by including not only the agencies that provide services for these youngsters, but also those departments who receive youth when they slip through cracks in the service system (e.g., corrections, substance abuse).

Successful interagency planning councils are comprised of individuals who have significant decision-making authority in their agencies. Members should assess the problems their own departments have in meeting the needs of transitional youth and develop a specific proposal for improving services within and across agencies. They should have the authority to share responsibility and resources, and should seek the active involvement of local service providers to ensure that their recommendations are implemented.

Several examples of success in overcoming systems barriers in the children's system can serve as models for systems serving transitional youth. In Virginia, the departments of Corrections, Mental Health, Mental Retardation and Substance Abuse, Social Services, and Education signed a memorandum of understanding to help communities address the needs of individuals with serious emotional disturbance (Boyd, 1992). Their efforts, including combined funding, resulted in a reduced reliance on residential care and increased recognition of the need to plan community-based services for youth with serious emotional disturbance. A comprehensive study of the group's venture led to enactment of Virginia's Comprehensive Services Act for At-Risk Youth and Families.

The State of Vermont recently completed a three-year assessment to evaluate the needs of the state's transitional youth. They have identified: (1) current services that exist to help Vermont teens transition to adult living, (2) perceived service needs that are not being filled, and (3) the need for coordination and a shared sense of vision to guide the development of services for this group (Barron, 1993).

Coordinate efforts at the local level. As noted previously, youth with serious emotional disturbance typically are involved in a variety of service systems, each of them operating independently of one another. This results in duplication and fragmentation of services. Within the mental health system, adult service providers have little incentive to plan for adolescents who may or may not eventually be eligible for their services (Koroloff, 1990).

To avoid these difficulties, many states and communities require *interagency case review* processes for the development of individualized treatment plans. These procedures should be expanded to address the particular needs of transitional youth. Specifically,

representatives from child and adult agencies need to pool their resources to coordinate existing services, advocate for services to fill the gaps, and purchase services that either don't exist or are not available.

Child and adult providers can establish *formal and informal working relationships* to promote communication, exchange of expertise, and agreements to provide services for transitional youth. For example, in-service training by vocational specialists can help mental health treatment programs gear their services to the specific needs of transitional youth. Mental health professionals can help school systems keep youth from dropping out. Even within the mental health system itself, formal agreements to extend child and adolescent services or to change eligibility for young adult services can make a marked difference in the ease with which youth transition from one system to another.

Advocate for the client. At the client level, *coordination of services by a single individual* -- a case manager, caseworker, or therapeutic case advocate -- can help ensure that the various system components are working together on behalf of transitional youth.

Health Care Reform and Financing Strategies

"The organization of community care for patients with chronic mental illnesses is seriously deficient. Most of these patients depend exclusively on underfinanced, fragmented, and often inaccessible public services...Patients lost to the system are commonly found in shelters or jails or on the streets." -- Mechanic and Aiken (1987)

The financing of mental health services often dictates the care an individual receives. Health insurance benefit designs that encourage inpatient care can lead to an overreliance on expensive hospitalization and 24-hour residential treatment that is often inappropriate. Fee-for-service or cost-based reimbursement encourages high levels of use.

Increasingly, managed care has come to be viewed as a solution to a series of problems associated with fee-for-service mental health and substance abuse treatment. In many locales, Medicaid mental health services have been the first target for implementation of managed care (Dangerfield & Betit, 1993; Minkoff, 1994), which has been described as "any technique that serves to control or direct the allocation and expenditure from the payer's perspective" (Wells, 1995).

In their efforts to control costs and improve access, managed care systems typically employ a variety of administrative and financing mechanisms, including utilization management, claims review, and capitation. Many who advocate managed care believe it can

create a comprehensive, integrated, consumer-centered community support system for people with serious mental illnesses. Others fear that managed care will result in underservice and lack of access for individuals with high-cost needs.

The benefits and risks of managed care. Transitional youth have traditionally had two major problems with existing service systems -- they are ineligible for many services, and the services for which they are eligible are often inappropriate. Managed care has the potential to correct these deficiencies, but risks are involved.

Eligibility. Many states have received waivers of Federal Medicaid regulations that allow them to increase Medicaid enrollment by eliminating narrow categorical eligibility, thus providing access to care for such groups as homeless individuals and older adolescents. However, other communities have used managed care as an opportunity to "tighten the belt" and concentrate services only on "high utilizers" among the chronically mentally ill, leaving the young ignored (Schinnar, Rothbard & Hadley, 1989).

Appropriateness. Many believe that capitation may force providers to deliver more appropriate mental health services. By attaching funds to a client rather than to a particular program or treatment, capitation may encourage the creation of services that are more responsive to an individual youth's needs. Also, when providers are at-risk for client care, they are more likely to seek less expensive, community-based alternatives to hospitalization. Thus, they can plan a configuration of services uniquely tailored to the individual and include such elements as room-and-board arrangements, supported housing, and vocational training (Dangerfield and Betit, 1993).

However, critics contend that the same financial incentives that prompt providers to be efficient may lead to underservice -- including services that are too brief in length and too minimal in intensity to be effective -- if an organization risks lower profits or actual financial loss by offering high-cost care. They fear that people with complex needs, including transitional and homeless youth, will be ignored at best and actively shunned at worst. At this time there is little research to suggest that a centralized authority or flexible resources foster innovation and better service delivery (Schinnar, Rothbard & Hadley, 1989; Yank, Hargrove & Davis, 1992).

The need for quality assurance. With the rush to cut health care costs, it is too easy to activate incentives to provide less care than an individual may need. Because there are few standards and little research to guide the level of care necessary for transitional youth, managed care organizations must be monitored closely to ensure appropriate outcomes, including improved quality of life, for youth with serious emotional disturbance.

Creative funding strategies for transitional youth. To succeed in making the transition to adult role functioning, transitional youth must receive services that are individualized, coordinated, comprehensive, and continuous as long as they are needed.

Funding that follows the individual across service systems, as well as through the age of majority, is a key component to promoting appropriate services for these youngsters. Although, several demonstration projects in child and adolescent and adult systems have used cross-system

funding mechanisms, no system has used resources that follow individuals from children's to adult services. Each of the following funding mechanisms should be viewed within the framework of funding that follows the individual.

Pooled/blended funding streams. One of the best ways to promote the needed coordination among service agencies is to blend funding streams. Services such as mental health, vocational rehabilitation, substance abuse, and corrections should contribute funds that help to decategorize services and promote coordination on behalf of transitional youth. In Arizona, the state legislature approved a demonstration project for individuals with chronic mental illnesses that combines funding to create multidisciplinary clinical teams. Team members arrange for all services needed by their clients, and they provide outreach, evaluation, family education, and support (Dickey & Cohen, 1993).

Creating new services through flexible funds. Flexible or wrap-around funds are resources made available to purchase noncategorical services for transitional youth, such as a job mentor, a paid roommate, or a bus pass (Behar, 1985). One of the greatest advantages of this kind of funding is its potential to identify and create those services that are needed but do not already exist.

Empowerment through direct cash. One of the more controversial financing strategies is to provide family members and transitional youth the funds to purchase services they select themselves. By providing the family or youth with control over the dollars, they become true consumers with direct power over their spending. Proponents believe this may result in a more responsive service system. Currently this kind of financing model exists primarily in the developmental disabilities field, and has not been explored sufficiently in mental health (Friedman, Burns & Behar, 1992).

Shared Risk. One of the difficulties in any creative financing for transitional youth services is that there is very little data upon which to predict appropriate cost. Thus, agencies that propose to manage a capitated budget, blended funding streams, or flexible funds for transitional youth are at risk of underestimating the need (particularly in the competitive spirit of contract bidding), and assuming financial loss or clinical liability (Dickey & Cohen, 1993). Payors, such as state agencies, need to share the risk to encourage the development of these systems.

Seeking a New Direction

When existing services are better coordinated and financed, youth with serious emotional disturbance are less likely to be lost in the transition to adult services. In addition, the development of new and innovative services -- such as model programs that combine sophisticated psychiatric treatment with hands-on vocational training -- can better serve those youngsters for whom existing services are not appropriate. Innovative approaches to meeting the needs of transitional youth are described in the next chapter.

INNOVATIVE APPROACHES

Programs for Transitional Youth

Employing Interdisciplinary Treatment Teams in Franklin County, Ohio

Franklin County, Ohio, has established interdisciplinary teams with flexible, wrap-around funding to serve transitional youth. The first team, created in 1990, resulted from a combination of factors. The county Alcohol, Drug Addiction and Mental Health (ADAMH) Services Board began to develop community alternatives for children and adolescents exiting the closing state hospital, and in doing so realized the need to plan special services for those youth too old for children's services and too young for adult programs.

At the same time, the adult system began implementing interdisciplinary Community Treatment Teams (CTTs) to help adults with serious mental illnesses remain in their communities. As the result of cooperation between officials on the ADAMH Board, the new children's hospital alternatives program, and the adult CTT's, one of the new teams was designated to serve transitional youth. This transitional team was located in an adult mental health agency that had an emergency screening program for children.

The team included five members with experience in both child and adult systems, including a vocational specialist, a nurse, and a child psychiatrist. Team members received referrals from children's crisis teams or the shared hospital program (a regional consortium), and they assessed and planned services for youth ages 16 to 22.

With initial funding from the adult program development budget, the team eventually received a combination of Robert Wood Johnson Foundation grant money and set-asides from state and local taxes. Two additional five-member teams have been added, and each of the three teams serves up to 50 youth per year. Additional referrals come from the Kids In Different Systems program, which identifies transitional youth involved with multiple agencies who need intensive mental health support.

Creating new services through flexible funding. Each team has \$10,000 in discretionary funds, and transitional youth who are enrolled in school have access to a \$350,000 fund jointly administered by various ADAMH Board agencies that serve children. With these flexible funds, transition teams can purchase existing services or support such innovative assistance as vocational mentors and paid roommates. In addition, in the absence of a full range of community residential services, discretionary dollars can be used to support youth in their own homes. For a first-person account of a youth's experience with a transition team, see Appendix E.

Building a more comprehensive system. Closer coordination among team members has resulted in some important system-level changes. Some mental health programs have extended their age limits to accommodate transitional youth. When Huckleberry House, a program for street youth, lost its federal funding several years ago, a combination of local resources -- including alcohol, drug abuse, and adult mental health dollars -- was used to continue the program. Huckleberry House develops independent living services for street youth not connected to any child or adolescent agency. However, some barriers remain, for example, most residential programs are licensed through child welfare agencies which maintain a strict age 18 criterion.

In addition, an interagency planning group was created to assess the needs of transitional youth in a wide range of systems, and to implement a much broader scope of services for these youngsters. Local efforts have been enhanced by state dollars obtained through federal IDEA funding. Transition planning with these dollars will include youth who are in educational programs, but are generally unknown to the school system (e.g., adolescents in residential programs).

Planning Multidisciplinary Treatment in the State of Vermont

The State of Vermont recently completed a three-year system planning grant from the Child, Adolescent and Family Branch of the Center for Mental Health Services, in which one of the goals was to plan for improved services to transitional youth. The results are summarized in *The Transition to Adulthood: Supports and Services for Vermont's Adolescents Experiencing a Severe Emotional Disturbance* (Barron, 1993).

One of the key recommendations is the development of a multidisciplinary team knowledgeable about the needs of transitional youth. This group will work with the local interagency case review teams to enhance the appropriateness of treatment plans for these youngsters.

Team members will include an employment specialist to address the employment needs of each youth and to develop local employment opportunities in the community; a supported housing specialist, to help youth find and maintain supported or independent housing; and a transition support specialist to help youth coordinate and gain access to such services as individual, group, or family counseling, case management, and specialized rehabilitation services.

A mental health staff member will be assigned to each secondary school to provide ongoing case management and specialized rehabilitation services for youth with serious emotional disturbance who are still in school. This teamwork is designed to ensure a comprehensive and holistic approach to meeting the basic needs of transition-aged youth with severe emotional disturbance. The goal of this assessment process will be to heighten the awareness of transition issues by providers, policy makers and administrators and lead to informal processes that improve transition services.

Adolescent Programs

Creating Mental Health Case Management in Seattle, Washington

In 1990, the King County Mental Health Division in Seattle, Washington, provided block grant funding to establish a street-based mental health case management service for homeless youth. Program participants were youth between the ages of 11 and 21 with serious emotional disturbance who were using the Youth Care/Orion Center, a multipurpose drop-in center in downtown Seattle. Though the case management program was administered by Seattle Mental Health Institute, a traditional mental health agency, case managers used innovative informal, and nontraditional engagement and treatment strategies. The block grant funding mechanism allowed flexibility which categorical fee-for-service mechanisms preclude.

Case managers used an interagency team model to support transition aged youth who were falling through service cracks. Team members, including the youth, his/her case manager, and representatives of children's and adult mental health services, vocational training, and housing programs, strengthened and consolidated services for youth to help them bridge the transition to adulthood. The effectiveness of the cross-system team lies in its ability to:

- create or enhance networks of people to fill gaps in care or add consistency to service delivery;
- include the youth as an equal player, which supports the developmental need for autonomy;
- stretch monetary resources or help identify new resources to provide continuity and avoid unnecessary duplication of services;
- maximize opportunities for cooperation among caretakers; and
- demonstrate to a youth the extent and strength of his or her support network.

This cross-system team allowed responsibility to be shared by adult and children's system representatives and is a blueprint for the services that so many troubled youth need.

An evaluation of the YouthCare/Orion Center mental health case management program includes a detailed description of each youth engaged in the case management service; a comparison of the characteristics of youth who chose not to engage with case managers and those who did; and a look at such outcomes as return to home community and school, engagement of families in treatment, housing placement, acquisition of entitlements, and employment (Vander Stoep et al., 1994).

Using Community and Educational Resources in Chicago, Illinois

Kaleidoscope. The Kaleidoscope Youth Development Program in Chicago provides unconditional, individualized support and services to young adults with emotional and behavioral problems. At the heart of Kaleidoscope's transition program is a no-rejection policy. All referrals come from the state departments of Child Welfare, Mental Health, and Corrections. Youth workers who serve as primary case managers, backed by a team of professional staff, provide flexible, wrap-around supports for independent living, employment, education, and community life.

The program has successfully placed youth in their own apartments in the inner-city. Kaleidoscope leases the apartments and pays rent directly to the landlord. If an apartment is damaged, the resident is held financially responsible, but the agency makes repairs.

Youth workers have funds to help clients purchase basic supplies for their apartments, and they visit them in their homes each week. Clients receive a weekly stipend for food, clothing, recreation, and transportation. Eventually, they use a portion of their stipend to save for their own apartments.

Kaleidoscope offers job development and job coach services, and sponsors recreational and social activities. In addition, Kaleidoscope staff teach clients about sexually transmitted diseases and birth control options, and ensure adequate prenatal care for pregnant youth. A family specialist works with the youth worker to ensure coordinated care for children, as well as continued support focused on the mother's needs (Clark, Unger & Stewart, 1993).

Thresholds. In the mid 1970s, the creators of the Thresholds Young Adult Program in Chicago realized that the rehabilitation needs of mentally ill adolescents were being inadequately addressed in the adult psychiatric system. In response, they designed a long-term, comprehensive, psychosocial rehabilitation program for transitional youth.

Participants complete their high school education in a licensed, accredited school that includes vocational preparation in the traditional clubhouse model. Youth spend three mornings a week in small academic classes and two mornings a week working on in-house food service or janitorial crews to learn job-readiness skills. In the afternoons, they attend recreational activities, group sessions on social problem solving, pre-vocational skills training, stress and medication management, and individual and group therapy sessions.

A community scholars program provides remedial education and preparatory classes to help youth who wish to pursue a higher education identify goals and improve study skills. Once they enter college or a vocational/technical school, this program offers such services as peer tutoring, advocacy, support groups, and personal assistance.

Three small group homes offer residential placements to about half of the adolescents in the program. Youth learn daily living and social interaction skills in an environment that stresses increasing privileges and responsibilities. The importance of peer leadership roles for empowering

and motivating youth is emphasized in housing and job-readiness activities. Young adults who are nearing graduation may participate in leadership training classes and supervise various activities at the agency.

The program also has a strong focus on families. Family members may participate in parent support and education groups and family therapy. Case managers enlist parents' aid in helping their children achieve independent living. The anticipated length of stay in the program is 2 to 4 years.

An ongoing evaluation of the Thresholds Program includes descriptions of participants, assessments of youths' pre- and post-intervention functioning on a variety of psychometric measures, and appraisals of program components (e.g., vocational training, supported employment) (Cook et al., 1994).

Developing Programs for Homeless Adolescents

Boston. Bridge Over Troubled Waters (Bridge), a private, nonprofit agency with headquarters in downtown Boston, Massachusetts opened in 1970 to provide street outreach to runaway and homeless youth. Today, with a budget of \$1.5 million, it offers comprehensive services to youth ages 16 to 21 living on the streets and in the community.

Each year, Bridge contacts about 3,000 youth through its outreach programs and engages 2,300 youth in services. Thirty-eight full-time staff, three part-time staff, and more than 200 volunteers provide services that include the following:

- street outreach;
- runaway crisis counseling and emergency shelter through 20 "host homes";
- substance abuse counseling;
- a center for prenatal care and parenting training;
- a mobile medical van;
- a dental clinic;
- AIDS prevention and education services;
- a drop-in center;
- education and pre-employment services;
- a transitional housing facility for 16- to 21-year-old homeless youth;
- a transitional housing facility for 16- to 21-year-old mothers and their babies;
- and
- cooperative apartments for 18- to 21-year-old youth.

Bridge creates an atmosphere of tolerance and respect for youth, offering services in a low-key, nonintrusive manner. In return, Bridge expects youth who become involved in services to act responsibly. The program provides most of its services in-house, but draws extensively on community resources for funding and volunteer support, particularly health care professionals to staff the medical van and dental clinic.

Bridge uses volunteer researchers to conduct yearly in-house evaluations of its program components, examining the characteristics of youth served and program outcomes. The program has

a management information system that collects intake, service, and outcome data for all service components (Pires & Silber, 1991).

Seattle. The Threshold Project in Seattle, Washington, is a residential treatment program jointly sponsored by the State of Washington Department of Child and Family Services, the University of Washington Adolescent Clinic, and YouthCare of Seattle. Threshold offers a series of progressively more independent living experiences to young homeless women ages 16 to 18 who have been sexually, physically, or emotionally abused or neglected, and who lack the ability to care for themselves.

The program includes three phases. During a 4- to 6-month stabilization period, clients are evaluated based on their willingness to take part in house activities, chores, and school. Young women who are ready to begin semi-independent living graduate to a house staffed by a live-in foster parent and two full-time child care staff members. Specific house rules are kept to a minimum to encourage individual responsibility, and residents are expected to work on employment, education, and independent living skills. The average length of stay in the second phase is 6 to 8 months.

As clients approach their 18th birthday, project staff prepare them to live independently in the community. Clients under 18 who are ready to graduate are moved to "independent" foster homes, where foster parents are specially trained to help the young women achieve independent living. Clients receive follow-up care from Threshold staff and attend weekly support meetings.

Evaluation of the Threshold Project includes comprehensive profiles of all women entering the program, identification of client needs and the services available to address them, and client outcomes related to their characteristics and service needs. Outcomes that are tracked include participation in program services, and discharge and 6-month post-discharge employment status, school attendance, residential stability, criminal activity, and drug/alcohol involvement (Schram & Giovengo, 1991).

Adult Programs

Applying the Clubhouse Model in Wichita, Kansas

The Breakthrough Club in Wichita provides support to young adults with serious mental illnesses through social and recreational activities, case management, supported employment, education, and transitional housing. All of these activities are based on the Fountain House consumer-managed clubhouse model.

Individuals age 18 and older with a history of mental illness can become members. They must agree to a mutual support policy and maintain their interest in membership after a period of orientation. The clubhouse philosophy creates an atmosphere of acceptance and promotes behaviors and attitudes that will help members become healthy, productive citizens (Clark, Unger & Stewart,

1993). Club members operate every aspect of the clubhouse from meals and maintenance to outreach and newsletter preparation.

A new Transition Age Program began in 1994 with funding from both the child mental health and the adult mental health agencies in Sedgwick County. It provides the same resources as the adult Breakthrough Club -- social and leisure activities, education, and supported employment opportunities -- to young people ages 16 to 24 who have a mental illness. This groundbreaking program, working to bridge the gap between children's and adult mental health services, succeeds in developing ownership and in breaking the stigma of mental illness for adolescents and young adults. The program is currently working to build a larger clubhouse and to identify more respite care resources (David Harper, personal communication).

Providing Support for Higher Education in Tucson, Arizona

Though many transitional youth do not complete high school, there is a significant portion who do, and who are capable of completing college. Their right to attend college without discrimination is guaranteed under the Americans with Disabilities Act (see Appendix C). However, they may need special support to help them be successful.

The Return to Learn program of the University of Arizona's Community Rehabilitation Division in Tucson offers a community-based, supported education alternative. The program provides such services as career exploration, assistance with applications and registration, study partners, training in study skills, 24-hour support, peer support groups, and liaisons with campus services, including disabled student resources and financial aid. The program is staffed by an instructional specialist and two student support facilitators.

Creating Programs for Homeless Adults

Westchester County, New York. Many transitional and homeless women who become pregnant have few social supports. The Center for Preventive Psychiatry (CPP), Inc., Mental Health Outreach Project for Homeless Families and Children serves mothers with young children living in motels in Westchester County. The program emphasizes early intervention and primary prevention.

CPP's two clinics comprise one of the largest outpatient mental health treatment programs for preschool children in the nation (Bassuk, 1990). Three sites serve homeless families -- a mobile outreach project in central Westchester, a centralized family drop-in center in Yonkers, and an on-site community center for families in northern Westchester.

Clinical services include individual and family treatment, psychological and psychiatric evaluation, mother/child groups, after-school groups for school-aged children, crisis intervention, advocacy, referrals to other service providers, and follow-up services as needed for families who

move into permanent housing. At the drop-in center, mothers can receive medical care, educational and legal advocacy, parenting skills, case management, housing assistance, and employment placement.

Program Evaluation and Research

What Have We Learned?

Increasingly, human service programs are being held accountable for the effectiveness of the programs they provide. To determine both cost-effectiveness and clinical outcomes, evaluation is a critical component of program design (Guba & Lincoln, 1989). Much is known about the developmental needs of youth with serious emotional disturbance and the problems that preclude their smooth transition to adulthood. There are, however, few rigorously designed research studies on the effectiveness of specific strategies designed to help these youngsters.

In particular, policy makers and service providers need to know more about what types of supports are needed for specific groups of transitional youth -- including depressed youth, gay and lesbian youth, youth from ethnic minority groups, youth with family histories of abuse, gang-involved youth, and pregnant homeless young women -- at the age of emancipation. In addition, future evaluations should focus on the impacts of various strategies which could prevent homelessness among high risk youth with serious emotional disturbance.

Study designs. There are a range of study designs that can contribute to a better understanding of transitional youth. Descriptive, cross-sectional studies of groups of 18- to 24-year-olds are useful in characterizing the needs of this population. The literature contains many recent articles describing the status of homeless youth and youth with serious emotional disturbance, but few studies focus specifically on the transition years. Little is known about the transitional differences between urban and rural populations, youth of different ethnicities, or youth from different child serving agencies. More prospective, longitudinal studies are also needed to document the effects of discontinuities between the child and adult service systems on youth with serious emotional disturbance, to identify high risk periods during the life course, and to assess treatment outcomes.

Program descriptions are fairly common in the literature (e.g., Clark, Unger & Stewart, 1993; Pires & Silber, 1991), but process evaluations, which would depict the inner workings of program implementation, or impact evaluations, which would document the outcomes of interventions, are uncommon. Several studies that examine post-discharge educational, vocational, residential, criminal, and treatment status of program participants (e.g., NACTS, NLTS) have not included comparison groups of nonparticipants, making it difficult to attribute follow-up status to the effects of programs.

Other studies with comparison groups contrast the outcomes of youth who choose not to participate or fail to participate fully with those who do participate (e.g., Wurzbacher, Evans & Moore, 1991). In these cases, inferences about program effectiveness are limited by potential

selection biases. Although several studies have employed randomized, controlled research designs to evaluate interventions for at-risk youth (e.g., Henggeler, Melton & Smith, 1992; Cauce et al., 1994), no research has focused specifically on transition-aged youth with mental illness or homeless transitional youth.

The need for systematic evaluation. The variability in definitions of serious emotional disturbance across studies and differences in sampling methods hinder comparability in studies focused on young adults with mental illnesses. Results also vary depending upon the demographic characteristics of study populations, as well as whether inpatient, outpatient, or untreated groups are sampled. The following recommendations are aimed at maximizing the utility of evaluations, and enhancing their methodological validity:

- Use comparable measures of success or adjustment across studies to enhance the power of the combined findings.
- View treatment outcome as multidimensional and multidirectional, with assessment of both positive and negative outcomes across a variety of dimensions (Prentice-Dunn, Wilson & Lyman, 1981).
- Select scales and instruments where the validity, reliability, norms, and characteristics of the standardization sample (particularly as they relate to ethnicity and school achievement) are known.
- Blind data gatherers to the condition of subjects' pre-treatment status, or group membership when there are control groups.
- Include control groups (e.g., no treatment, minimal treatment, and/or "treatment as usual") to strengthen inferences about treatment effects.
- When possible, randomly assign participants to intervention and control groups to eliminate a number of biases and strengthen the validity of the results.
- Explain the complexities of the intervention -- attitudes, expectations, treatment interactions, and organizational structures -- to promote understanding of the "independent variable".
- Carry out post-discharge follow-up to address the issue of whether treatment gains are sustained or have an effect on the clients' broader life domains.
- Study interventions in multiple sites to determine whether the effects can be generalized.

Though follow-up studies are invaluable, they usually require resources that are beyond the scope of clinical and administrative budgets, and they are often plagued by attrition (Pfeiffer, 1989). Also, it can be difficult to coordinate evaluation efforts across multiple sites. Evaluations deserve a coordinated effort from funding agencies so that many of the methodological weaknesses inherent in low-budget evaluations can be overcome.

Where Do We Go From Here?

It is clear that a handful of creative programs have been designed to help youth with serious emotional disturbance make a successful transition to adulthood. Other programs for children or young adults have included services for transitional youth. Still, while much is known about the needs of this group, little is known about the effectiveness of the programs that have been created to serve them. Some recommendations for enhancing service delivery and evaluation efforts at the federal, state, and local level follow in the final chapter.

SUMMARY AND RECOMMENDATIONS

The plight of youth in transition with serious emotional disturbance is grave. As a group, these youth are undereducated, underemployed, and have limited social supports. With these deficits, they are at high risk for homelessness, criminal activity, drug use, and dependence on public support, as well as low self-esteem and poor quality of life.

Both the child and adult service systems have failed to claim responsibility for helping children who have serious emotional disturbance make the transition to adulthood. This discontinuity of service is supported by strict eligibility criteria, rigid funding streams, and practices that do not take into account the developmental needs of these youngsters. Without changes in policies and financial support to strengthen research and develop services for transitional youth, the picture will remain grim.

Recommendations for Transition Planning

Koroloff's (1990) components of an exemplary transition policy serve as a basis for the recommendations that follow. Ideally, supports which enable youth with serious emotional disturbance to make the transition to adulthood should be:

- **provided locally**, with identification of children who need transition planning at an early age;
- **considered automatic** and therefore not dependent on a unique request for each individual youth;
- **operated in a variety of settings**, so that schools are not the only agencies responsible for identifying eligible youth and initiating transition planning;
- **organized by a single individual or system** that will be responsible for planning and delivering services over a period of time;
- **planned and implemented with the active involvement of parents and youth** (parents may be defined broadly to include relatives, foster parents, community advocates, or other individuals who have a long-term commitment to the youth);
- **coordinated at the state and local level** by interagency and interdepartmental groups who can plan services, resolve disputes, and facilitate the integration of service systems;

- **developed with the participation of adult agencies** before the youth leaves the child and adolescent system; and
- **construed broadly** to include all aspects of successful, independent adult living.

Recommendations for Action

The following recommendations are based on the principles described for a system of care for transitional youth and derived from the literature reviewed in previous sections.

At the federal level

- All youth with serious emotional disturbance should be guaranteed the right to transition planning. Federal legislation, much like that found in the IDEA, should be enacted to guarantee the right to appropriate transition planning and the provision of needed services for youth with serious emotional disturbance who are exiting children's services.

The IDEA legislation itself should be extended to encompass youth in nontraditional school settings such as street-based programs, residential programs, detention, and correctional facilities. Funding for IDEA activities should be contingent on interagency cooperation.

- The system of care for transitional youth should be based on a solid core of research. Funding agencies need to make this a priority population and provide grant support for technical assistance, research, service demonstrations, and evaluation to help guide the development of appropriate services.
- Federal agencies should model the interagency cooperation needed to serve transitional youth. In particular, research and service grants should be coordinated across the various federal agencies that serve children and adults with mental illnesses.

In addition, a multiagency federal commission should be convened to seek input from states, providers, youth, and families; establish priorities for this population; and make recommendations for federal action. Federal agencies that determine definitions affecting transitional youth should coordinate their efforts to help reduce the barriers to services that these varied definitions produce.

- Flexible funding should be provided for transitional services to homeless youth so that reimbursement is not tied to strict compliance with traditional treatment patterns.

At the state level

- Transitional youth are involved in multiple service systems. States should establish a plan to address their needs through interagency planning councils and multidisciplinary activities.
- States should support demonstration projects to test and evaluate interventions that have the potential to be adopted statewide.
- State agencies should develop formal and informal mechanisms to exchange information and share resources to serve transitional youth.
- State agencies that have both child and adult counterparts should develop shared responsibility for youth with serious emotional disturbance and provide the funds to address their needs adequately.

At the local level

- Some of the most encouraging developments in this area come from local initiatives. Local agencies should work together to promote formal and informal mechanisms for interagency cooperation. Families and youth must be included in this process.
- Schools are the logical point for first identification and referral for mental health problems. To promote primary prevention, many services should be located in schools. However, schools cannot carry this burden alone. Education officials should work closely with other children's agencies to alleviate problems faced by youth with serious emotional disturbances in all service settings.

A Good Beginning

Without appropriate programs and the necessary funding to support them, transitional youth suffer the frustration of trying to meet adult roles that they are developmentally unprepared to accept. The result is that the youth, and society at large, reap the consequences of increasing homelessness, crime, and dependency. The creative, fledgling efforts that are being made to address the needs of transitional youth in communities around the country are an excellent first step in bridging the gaping service system discontinuities this population must face.

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APPENDIX A

Definitions of Serious Emotional Disturbance

DEFINITIONS OF SERIOUS EMOTIONAL DISTURBANCE

Center for Mental Health Services

Pursuant to Section 1912(c) of the Public Health Service Act, as amended by Public Law 102-321, "children with a serious emotional disturbance" are persons:

- from birth up to age 18,²
- who currently or at any time during the past year,³
- have had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within DSM-III-R,⁴
- that resulted in functional impairment which substantially interferes with or limits the child's role or functioning in family, school, or community activities.⁵

These disorders include any mental disorder (including those of biological etiology) listed in DSM-III-R or their ICD-9-CM equivalent (and subsequent revisions), with the exception of DSM-III-R "V" codes, substance use, and developmental disorders, which are excluded unless they co-occur with another diagnosable serious emotional disturbance. All of these disorders have episodic, recurrent, or persistent features; however, they vary in terms of severity and disabling effects.

²The definition of serious emotional disturbance in children is restricted to persons up to age 18. However, it is recognized that some states extend this age range to persons less than age 22. To accommodate this variability, states using an extended age range for children's services should provide separate estimates for persons below age 18 and for persons age 18 to 22 within block grant applications.

³The reference year in the definition refers to a continuous 12-month period because this is a frequently used interval in epidemiological research, and because it relates closely to commonly used planning cycles.

⁴DSM-IV has been published. The 10th revision of the International Classification of Diseases (ICD-10) will probably not be adopted officially in the United States until late in the 1990s. These revised nomenclatures are likely to affect both the language of mental disorders and the types of disorders currently included or excluded from this definition. Accordingly, the definition will be updated by CMHS as appropriate.

⁵Functional impairment that "substantially interferes" will be operationally defined as part of the process of developing standardized methods for estimation.

Functional impairment is defined as difficulties that substantially interfere with or limit a child or adolescent from achieving or maintaining one or more developmentally appropriate social, behavioral, cognitive, communicative, or adaptive skills. Functional impairments of episodic, recurrent, and continuous duration are included unless they are temporary and expected responses to stressful events in the environment. Children who would have met functional impairment criteria during the referenced year without the benefit of treatment of other support services *are* included in this definition.

Department of Education (34 CFR 300.5(b)(8))

Current regulations. Under current federal regulations, the term "serious emotional disturbance" is defined by the Department of Education as described below.

Serious emotional disturbance means a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree, which adversely affects school performance:

- an inability to learn which cannot be explained by intellectual, sensory, or health factors;
- an inability to build or maintain satisfactory interpersonal relationships with peers and teachers;
- inappropriate types of behavior or feelings under normal circumstances;
- a general pervasive mood of unhappiness or depression; or
- a tendency to develop physical symptoms or fears associated with personal or school problems.

The term includes children who have schizophrenic disorders, but does not include children who are socially maladjusted, unless it is determined that they are seriously emotionally disturbed.

Suggested revisions. Congress required the Department of Education to issue a Notice of Inquiry to solicit public comment concerning the need for a change in this definition, and specifically whether to adopt the revised definition recommended by the Mental Health and Special Education Coalition. Although the period of public comment is complete, the Department has not decided what changes, if any, will be made.

The Coalition suggested deleting the term "serious emotional disturbance" and replacing it with "emotional or behavioral disorder," defined as follows:

The term emotional or behavioral disorder means a disability characterized by behavioral or emotional responses in school programs so different from appropriate age, cultural, or ethnic norms that they adversely affect educational performance. Educational performance includes academic, social, vocational, or personal skills. Such a disability:

- is more than a temporary, expected response to stressful events in the environment;
- is consistently exhibited in two different settings, at least one of which is school-related; and
- is unresponsive to direct intervention applied in general education, or the child's condition is such that general education interventions would be insufficient.

Emotional or behavioral disorders can co-exist with other disabilities. This category may include children or youth with schizophrenic disorders, affective disorders, anxiety disorders, or other sustained disorders of conduct or adjustment when they adversely affect educational performance.

Administration on Developmental Disabilities

Under current legislative definition, the term developmental disability means a severe, chronic disability of a person 5 years of age or older that:

- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is manifested before the person is 22 years old;
- is likely to continue indefinitely;
- results in substantial functional limitations in three or more of the following areas of major life activity: (a) self-care, (b) receptive and expressive language, (c) learning, (d) mobility, (e) self-direction, (f) capacity for independent living, and (g) economic self-sufficiency; and
- reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are of lifelong or extended duration and are individually planned and coordinated; except that such term, when applied to infants and young children, means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

The Social Security Administration: Children's SSI Program

To qualify for Supplemental Security Income (SSI), children must have impairments that are of "comparable severity" to impairments that would prevent an adult from working.

Sequential evaluation. Social Security Administration (SSA) rules establish a sequential evaluation process for children that is comparable to the one used for adults, and includes an assessment of how the child develops and functions compared to other children the same age. The Disability Determination Service (DDS) examiner must follow the 4-step evaluation process in this order:

- **STEP 1:** Is the child engaged in substantial gainful activity? If a child is engaging in substantial gainful activity (defined as earning at least \$500/month), the examiner will find the child not disabled. If not, the child moves to the next step in the sequence.
- **STEP 2:** Does the child have a severe impairment or combination of impairments? SSA defines a severe impairment as one that causes more than a minimal or slight limitation in a child's ability to function in an age-appropriate manner. If this level of impairment is found, the examiner will go on to the next step. If not, the examiner will find the child not disabled.
- **STEP 3:** Does the child's impairment, or combination of impairments, meet or equal a listing? If a child's impairment matches one of the conditions on SSA's Listing of Impairments, and the impairment is expected to last 12 months or result in death, the examiner will find the child disabled. The listing consists of 13 body systems that contain about 100 specific conditions. One of the listing sections is 112.00 -- Mental and Emotional Disorders. If the impairment does not match one that is on the list, the examiner will determine if the impairment is equivalent in severity to one that is on the list. If so, the DDS will find the child disabled. If not, the examiner will go to step 4.
- **STEP 4:** Does the child nevertheless have an impairment of comparable severity to that which would disable an adult? The examiner must determine if the impairment impacts on the child's ability to function independently and effectively in an age-appropriate manner. The examiner uses the individualized functional assessment. Based on this assessment, the child is determined to be disabled or not.

Structure of the listing. Each listing has two paragraphs -- A & B. A covers the clinical characteristics of the disorder, and B covers the functional impairment. To meet a listing a child must satisfy both paragraphs. There are 11 diagnostic categories that roughly correspond to the following:

112.02	Organic mental disorders
112.03	Psychotic disorders
112.04	Mood disorders
112.05	Mental retardation
112.06	Anxiety disorders
112.07	Mental disorders with physical manifestations (e.g., tic disorder)
112.08	Personality disorders
112.09	Psychoactive substance dependence disorders
112.10	Pervasive developmental disorders
112.11	Attention Deficit Hyperactivity Disorder
112.12	Developmental and emotional disorders in children under 1 year of age

Paragraph B elucidates functional limitations as they apply to children in different age groups (birth to 1 year, 1 to 3 years, 3 to 18 years), and evaluates 6 domains within each age group -- cognition or communication; social functioning; personal or behavioral (over 3 years); concentration, persistence, and pace (over 3 years); motor skills (under 1 year); and responsiveness to stimuli (under 1 year).

The level of severity required differs in the different age groups. The key factor is that the limitation must interfere "seriously" with the child's ability to function independently and effectively on a sustained basis, according to age-appropriate expectations.

APPENDIX B

Longitudinal Data Bases

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LONGITUDINAL DATA BASES

Four longitudinal studies, each of which followed a group of adolescents with serious emotional disturbance into the age of transition, are referred to extensively in this paper. A brief description of study participants and methodologies follows.

National Longitudinal Transition Study of Special Education Students

The first study is the National Longitudinal Transition Study of Special Education Students (NLTS) by the Stanford Research Institute (Wagner, Blackorby & Hebbeler, 1993; Wagner, et al., 1991, 1992; Marder, 1992; Valdes, Williamson & Wagner, 1990). The NLTS is a study of 8,408 students, including 779 students whose primary disability was serious emotional disturbance, who were in secondary school special education classes in 303 school districts across the country during the 1985-86 school year.

Data were collected in 1987, 1989, and 1990 from telephone interviews and mail questionnaires with youth and/or parents, from surveys of teachers and school administrators, and from students' school records. No standardized instruments were administered. Subjects in the NLTS study were ages 15 to 23 at the time of the 1987 interview. All reference to the NLTS participants are specifically to those with serious emotional disturbance, unless otherwise noted.

Since one of the central questions about transitional youth is what becomes of them when they reach the age of majority or leave the children's system, two subgroups of the NLTS database are of particular interest in the current discussion -- those age 19 and older, and those who left school, either by graduating, dropping out, aging out, or being permanently expelled/suspended. Separate analyses were made of youth who were out of school by the end of the 1986-87 school year. This data set was comprised of 1,990 participants, 222 of whom had serious emotional disturbance. Data were then analyzed for similarities and differences between youth who were out of school less than 2 years and those who were out 3 to 5 years.

It is important to keep in mind that many of the results of this study are reported as percentages of certain groups (e.g., students with serious emotional disturbance); however, these percentages were weighted to represent all youth enrolled in special education in the 1985-86 school year. Thus, for example, the subgroup of 1,990 participants who had been out of school since 1987 or before was weighted to represent the 3,046 youth who left school by September 1987 but did not have complete interview data for both the 1987 and 1990 waves.

Additionally, these researchers constructed a "general population" comparison group of youth who had been out of school for the same period of time, whose results were weighted so that they represented the same distribution of gender, head of household, education, and ethnic background as

youth with disabilities (Wagner et al., 1992). The group from which this data were constructed left school between 1979 and 1982, whereas the NLTS sample left between 1983 and 1987; thus, there may be some minor differences due to the time sampled. References to the general population refer to this weighted group unless otherwise stated.

National Adolescent and Child Treatment Study

The second study is the National Adolescent and Child Treatment Study (NACTS), conducted by the Research and Training Center for Children's Mental Health at the Florida Mental Health Institute (Silver et al., 1992; Prange et al., 1992; Greenbaum et al., 1991; Kutash et al., 1995). The NACTS followed 812 youth with serious emotional disturbance from six states.

Participants came from 94 special education programs and 27 residential mental health facilities. At the outset of the study, youth were ages 8 to 18 years. Half were being served through special education, and the other half were in residential mental health facilities. Participants were interviewed at baseline and then annually for 6 years. At each point, several instruments and semi-structured interviews were used with each youth.

During baseline, the fourth, and the final interviews, participants were administered the Diagnostic Interview Schedule for Children (DIS-C). A semi-structured telephone interview was conducted with the child's parent/guardian to administer several instruments and to obtain information about the child's social, developmental, and medical history, and receipt of services. Case records were also reviewed. Of particular interest to the current discussion are the results from the last wave of interviews because youth ranged in age from 14 to 24 years, clearly encompassing a large portion of transitional youth. Several analyses have examined some questions specifically in the 17-plus age group.

The Youth in Transition Study

The Youth in Transition (YIT) Study (Silver, 1993; Silver, 1995a; Silver, 1995b; Silver, Unger & Friedman, 1994) is based on a sample drawn from participants in the larger NACTS study. A random sample of youth was selected from a pool of 359 youth who were 18 to 22 years old in 1990, and had completed the youth and parent interview in 1989. The YIT study consisted of face-to-face interviews conducted in 1990 with 209 youth equally distributed between the special education and residential NACTS populations.

Participants were located in 95 cities across eight states at the time of the interview. The semi-structured interview contained questions about young adults' living, learning, working, and social experiences. It included information on secondary and post-secondary education and training, employment history, income, marital status, social involvement, and receipt of public-sector services.

McGraw Center Follow-up Study

The McGraw Center Follow-up Study, conducted by the Research Department of Seattle Children's Home, was launched in 1981 with the opening of Washington State's first publicly-funded residential treatment facility for severely psychiatrically impaired youth (Vander Stoep, 1991). Subjects in the study were the first cohort of 86 adolescents who were discharged consecutively from the McGraw Center Residential Treatment facility between 1981 and 1987.

Unlike the previous three studies, this study population included only the most severely impaired youth with serious emotional disturbance. To be eligible for admission to residential treatment, applicants had to be within the normal range of intelligence and have a severe psychiatric impairment corroborated by a clear diagnosis. So, while in general less than 5% of the population of youth with serious emotional disturbance have diagnoses of schizophrenia, 29% of this sample had diagnoses of schizophrenia and other thought disorders. Half of the cohort had affective disorders, and 27% had conduct disorders. There were equal number of males and females in the study cohort. The cohort included a fairly narrow age range of late adolescents with 85% between the ages of 16-18 years at discharge from treatment.

Participants in the McGraw Study were interviewed annually through their 5-year discharge anniversary. The interviews included administration of a life course questionnaire that assessed residential, vocational, financial, and treatment status. Several psychometric instruments which measured symptomatology and quality of life were also administered. At the time of the 3-year interview, 94% of the cohort were aged 18-22 years. Outcomes for this subgroup are included in this paper. For some analyses, outcomes were examined by "year of life", from 17 through 20. Using the date of discharge as the focal point, data for each subject were organized by the age the subject turned during the year prior to and the five years after discharge and were then grouped by year of life. This type of analysis allowed investigators to focus on events close to the time when adolescents must sever ties to children's services.

APPENDIX C

Conducive Laws and Policies

CONDUCTIVE LAWS AND POLICIES

A description of federal laws and programs that can impact transitional youth follows. No laws are specifically targeted to transitional youth with serious emotional disturbance; they are targeted to all students with disabilities, homeless or runaway youth, youth in foster care, or youth in juvenile justice systems. However, because many transitional youth fall into these other categories, the laws and policies described below may offer federal dollars, state programs, or a basis for litigation for transitional youth with serious emotional disturbance.

The Individuals with Disabilities Education Act (IDEA)

The following summary is taken from Florida Department of Education (1993). In October, 1990, Congress enacted Public Law (P.L.) 101-476, the Individuals with Disabilities Education Act (IDEA), which amended the Education of the Handicapped Act. One of the important changes was the inclusion of transition services as one of the areas to be addressed in individual education plans (*Federal Register*, September 29 and October 27, 1992).

In defining transition, IDEA includes requirements that directly affect how schools provide transition services for students with disabilities who are age 16 or older. Transition services are defined as

a coordinated set of activities for a student, designed within an outcome-oriented process, that promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation.

The coordinated set of activities must be based on the individual student's needs, taking into account the student's preferences and interests and including such services as instruction, community experiences, the development of employment and other post-school adult living objectives, and, if appropriate, the acquisition of daily living skills and functional vocational evaluation (34 CFR 300.18). The identification of transition services is required for all students age 16 or older with a disability in conjunction with their individual education plans (34 CFR 300.346). Individual transition plans (ITPs) are meant to be an integral part of the student's overall plan to result in a comprehensive blueprint for his or her future.

Where appropriate, IDEA encourages transition planning for students younger than 16. This may be relevant especially for youth with serious emotional disturbance, who may drop out of school when they reach age 16. Though the legislation requires a minimum of 2 years of transition planning, youth with serious emotional disturbance may require an ITP that spans 5 or 6 years.

Individualized transition plans. Transition plans are modeled on the individual education plans. Every ITP must include a statement of the needed transition services, and, if appropriate, each participating agency's responsibilities and/or linkages, or both, before the student leaves the school setting (34 CFR 300.346).

The ITP should also contain a statement of the desired post-school outcome. Areas to be considered in developing this statement may include, but are not limited to, post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, linkage with adult services, independent living, and community participation.

Every ITP meeting should include the student, his or her teacher and parents; the local education agency (LEA) representative, staff of other agencies likely to be responsible for providing or paying for transition services (34 CFR 300.344), and others at the discretion of the parents or the school district. Participating agencies are required to provide or pay for any transition service that the agency would otherwise provide to students with disabilities who meet eligibility criteria of the agency (34 CFR 300.347). If agreed-upon services are not provided, the group must identify alternative strategies to meet the objectives.

IDEA requires states to describe the role that each agency plays in providing or paying for services required by students with disabilities. They must further implement interagency agreements that (1) define the financial responsibility of each agency for providing children who have disabilities with a free and appropriate public education; (2) establish procedures for resolving interagency disputes among agencies that are parties to these agreements; and (3) establish procedures under which LEAs may secure reimbursement from agencies that are parties to the agreements (34 CFR 300.152).

Little funding or enforcement. Clearly IDEA has some power to improve outcomes for transitional youth. However, there is little money that accompanies the law, and no requirement that states create a budgetary line item to provide for full implementation. In essence, it provides a basis for litigation, but no means of broad implementation.

In the absence of funding, the law goes largely ignored in many states. Furthermore, once a student drops out of school, he or she is no longer eligible for an ITP, and there is no mandate that an existing ITP be fulfilled. Thus, for many youth with serious emotional disturbance, unless the transitional planning is extremely effective in preventing them from dropping out, the IDEA legislation will have little impact on their lives.

The Florida Network, housed in the department of Special Education at the University of Florida, is a technical assistance center for IDEA transition planning. The Network holds workshops and conferences, produces and disseminates information on successful transition planning, and publishes a semiannual newsletter, *Florida Network News*. While there is no current focus specifically on youth with serious emotional disturbance, the Network plans to develop special resources for this group.

The Carl D. Perkins Vocational and Applied Technology Act

The Carl D. Perkins Vocational and Applied Technology Act (P.L. 101-392) provides vocational education opportunities for students with disabilities and other youth with special needs. The new Act (an amendment to the Carl D. Perkins Act of 1984, P.L. 98-524) focuses on technological training. It greatly expands the federal government's job-related education efforts, and emphasizes service to special populations, including individuals with disabilities. Districts that apply for funds under this Act must meet the following requirements for individuals with disabilities:

- ensure equal access to recruitment, enrollment, and placement activities for the full range of vocational education programs and activities;
- afford the rights and protection guaranteed to students with disabilities under IDEA while in vocational education programs and activities;
- assist students with disabilities in fulfilling the transition service requirements of IDEA;
- assess the needs of, and provide support services to, students to assure successful completion of vocational education programs in the most integrated setting;
- provide supplemental services, including curriculum modification, equipment modification, classroom modification, supportive personnel, and instructional aides and devices;
- provide guidance, counseling, and career development activities; and
- provide counseling and instructional services to facilitate transition from school to employment and career opportunities.

The Americans with Disabilities Act (ADA)

The purpose of the Americans with Disabilities Act (ADA, P.L. 101-336) is to extend to people with disabilities civil rights similar to those available on the basis of race, color, gender, national origin, and religion through the Civil Rights Act of 1964. It prohibits discrimination on the basis of disability in private sector employment, government services, public accommodations, transportation, and telecommunications services.

The ADA has very specific regulations about access to institutions of higher education that permit students with psychiatric disabilities to request needed accommodations, such as longer times to complete examinations. A student on leave because of a disability cannot be denied reentry. The

institution does not need to provide personal services, such as an in-class aide, but cannot exclude students who use such resources. Similarly, institutions do not have to provide any tutoring beyond what is normally available, but they cannot prohibit the student from receiving additional assistance.

The Rehabilitation Act of 1973 and Amendments of 1992

The purpose of the Rehabilitation Act of 1973, as modified by the Rehabilitation Act Amendments of 1992, is to empower individuals with disabilities to achieve maximum employment, economic self-sufficiency, independence, and inclusion in society. To this end, the Rehabilitation Act promotes interagency cooperation for individuals eligible for services under this Act, the IDEA, and the Carl D. Perkins Vocational and Applied Technology Act.

The Runaway and Homeless Youth Act (RHYA)

The Runaway and Homeless Youth Act (RHYA), Title III of the Juvenile Justice and Delinquency Prevention Act of 1974 (P.L. 93-415), provides for community-based alternatives to incarceration to help runaway youth reunite with their families. Title III was amended to include services for homeless youth when the Act was reauthorized in 1977. This Act is overseen by the Family and Youth Services Bureau of the Administration for Children, Youth, and Families in the U.S. Department of Health and Human Services.

Through RHYA, host programs and emergency shelters across the country act as key entry points for runaway and homeless youth, providing comprehensive crisis intervention, stabilization, and aftercare services and referrals for youth in need. RHYA had four primary goals -- (1) to alleviate the problems of runaway youth; (2) to reunite young people with their families and resolve family problems through counseling and other services; (3) to strengthen family relationships and encourage stable living conditions for youth; and (4) to help young people decide upon a future course of action.

Many of these runaway and homeless youth centers offer a variety of services for transitional living, HIV and drug prevention, street outreach, physical and sexual abuse counseling, health care, job readiness, suicide prevention, and education. Since 1988, 10% of the annual RHYA appropriation is earmarked for activities that strengthen alternatives to the child welfare, mental health, and juvenile justice systems. These activities include a national hotline for runaway youth, discretionary research and demonstration projects, and training and technical assistance for service providers. Regional networks representing each of the 10 federal regions currently oversee training and technical assistance efforts (National Network of Runaway and Youth Services, 1991).

The Transitional Living Grant Program for Homeless Youth

The 1988 amendments of the RHYA created the Transitional Living Grant Program for Homeless Youth (TLP), the only federal program aimed at helping older youth who have no family or state support in their transition to adulthood. TLP authorizes grants and technical assistance to public and private, nonprofit agencies to establish and operate transitional living projects for homeless youth ages 16 to 20.

Through these programs, homeless youth are eligible for an array of services for up to 18 months, including shelter, education, vocational training, mental and physical health care, and the development of basic life skills. This program was funded for the first time in Fiscal Year (FY) 1990 (National Network of Runaway and Youth Services, 1991).

The Independent Living Programs for Youth in Foster Care

The Independent Living Programs for Youth in Foster Care was created in 1986, through the Consolidated Omnibus Reconciliation Act of 1985 (P.L. 99-272), to amend Title IV-E of the Social Security Act. The program established independent living projects as a justifiable and necessary function of state foster care programs for young people who become too old for foster care or are emancipated. Services are for youth age 16 and older for whom Title IV-E foster care maintenance payments are being made. These services aim to:

- enable participants to seek a high school diploma or its equivalent, or take part in appropriate vocational training;
- provide training in daily living skills, budgeting, locating and maintaining housing, and career planning;
- integrate and coordinate services otherwise available to participants;
- conduct outreach to attract youth who are eligible to participate in the program; and
- provide each participant a written transitional independent-living plan based on an assessment of his or her needs and incorporated into his or her case plan.

Federal monies for independent living are allocated to the states. State child welfare agencies in turn often contract with community-based, nonprofit organizations to provide independent living services. The first monies for this program were granted to states in FY 1987 (Allen, Bonner & Greenan, 1988; National Network of Runaway and Youth Services, 1991).

The Young Americans Act (YAA)

The Young Americans Act (YAA) was enacted as part of the Human Services Reauthorization Act of 1990. The Act calls for a national youth policy that ensures the rights of young people, and promotes development of a continuum of needed educational, health, and social services for those youth whose families cannot assure their well-being.

The YAA also established the Administration for Children, Youth, and Families (ACYF), and created a Federal Council on Children, Youth, and Families and a White House Conference on Youth. The Act allows the commissioner of ACYF to make grants to states to fill service gaps, and to enhance planning and coordination of services to children, youth, and families. Ninety percent of appropriations must be earmarked for state grants (National Network of Runaway and Youth Services, 1991).

The Stewart B. McKinney Homeless Assistance Act

The Stewart B. McKinney Homeless Assistance Act was enacted in 1987 and amended in 1990 (P.L. 100-77). The Act establishes a federal commitment to assist homeless individuals and families with children. McKinney programs for which homeless youth are eligible include those listed below.

- The Federal Emergency Management Agency (FEMA) is an emergency food and shelter program.
- The Emergency Shelter Grants Program funds state and local governments to support nonprofit agencies that provide emergency shelter and essential services.
- The Health Care for the Homeless program provides grants to public and nonprofit health care providers to deliver health care to homeless people.
- The transitional housing component of the Supportive Housing Demonstration Program makes grants to public and private, nonprofit entities to provide housing and supportive services for homeless people. Homeless individuals with mental disabilities and homeless families and children are a special focus of this program.
- The Education for Homeless Children and Youth program funds states and communities to increase access to education for homeless children and youth.
- The Projects for Assistance in Transition from Homelessness (PATH) program provides formula grants to states and territories to fund community-based services for homeless people with serious mental illnesses.

The Job Training Partnership Act (JTPA)

The Job Training Partnership Act (JTPA), enacted in 1982, created national employment and training programs for low-income people, including those who are homeless. Under Title II-A of JTPA, funds are distributed to states and, through them, to some 640 service delivery areas that serve approximately 1 million people annually.

APPENDIX D

Technical Assistance/Research and Training Centers

TECHNICAL ASSISTANCE/RESEARCH AND TRAINING CENTERS

Center for Psychiatric Rehabilitation

Research and Training Center
Sargent College of Allied Health Professions
Boston University
730 Commonwealth Avenue
Boston, MA 02215
(617) 353-3549
William Anthony, Ph.D., Director

The Florida Network (IDEA transition planning)

Department of Special Education
P.O. Box 117050
University of Florida
Gainesville, FL 32611-2503
(904) 392-0701, ext. 267, 269
Jean Repetto, Ed.D., Director

National Resource Center on Homelessness and Mental Illness

Policy Research Associates, Inc.
262 Delaware Avenue
Delmar, NY 12054
(800) 444-7415
Deborah Dennis, M.A., Director

Research and Training Center for Children's Mental Health

Florida Mental Health Institute
13301 Bruce B. Downs Blvd.
Tampa, FL 33612-3899
(813) 974-4657
Robert Friedman, Ph.D., Director

Research and Training Center on Family Support and Children's Mental Health

Regional Research Institute for Human Services
Portland State University
P.O. Box 751
Portland, OR 97207-0751
(503) 725-4040
Barbara Friesen, Ph.D., Director

Thresholds National Research and Training Center on Rehabilitation and Mental Illness

2001 North Clybourn Ave, Suite 302
Chicago, IL 60614
(312) 348-5522, ext. 2222
Judith Cook, Ph.D., Director

APPENDIX E

The Transitional Community Treatment Team

THE TRANSITIONAL COMMUNITY TREATMENT TEAM

By Michelle Antholine

I was first hospitalized in 1988 because I wanted to kill myself. I was unhappy with myself, I hated myself and was extremely upset over school and the thought of moving. I had a hard time with school because I was learning disabled, but was not diagnosed, therefore I felt stupid. I would not talk in school unless called upon and my answer was always "I don't know." At that time my father was out of a job and was talking about moving to Connecticut for my senior year of high school. I didn't have many friends, but the thought of not having a soul was terrifying to me. I thought it was strange that I really wanted to die over this, but I really did. I began to sink deeper and deeper into a depression, had more thoughts of suicide and upon initial counseling it was suggested that my problems were much more deeply rooted than I was willing to recognize.

I was first hospitalized in a children's hospital where my eating disorder, anorexia was discovered. After that hospitalization I began self-mutilation and continued to slip into a deep black depression. Because of insurance I had to switch doctors, only my doctor had me hospitalized almost my whole senior year of high school. I did not trust this doctor, in fact, I did not trust any doctor and my subconscious was very carefree to keep my secrets buried because I did not feel safe enough to recognize the root of my illness. It took 3 years of intense therapy before I allowed the abuse to come to conscious level.

I was told by my uncle that psychiatrists and anyone related to that field were crazy people who would hurt me and make me crazy. My uncle had abused me for 14 years. He abused not only sexually but also physically, emotionally and included me in satanic ritual abuse. Therefore, I gave doctors the answers I thought they wanted while I deteriorated mentally. My family was told that I would never be able to function in society again, I'd always have to be hospitalized.

For the next year I bounced around from doctor to doctor and from hospital to hospital. Sometimes it was because the psychiatrist would tell me that they didn't want to deal with me. I played a lot of games and I never trusted. I have been on every anti-depressant there is and I have had ECT and nothing worked. Eventually I was given the diagnosis of Borderline Personality Disorder, Major Depression, Anxiety Disorder, Anorexia Nervosa, Bulimia and Post Traumatic Stress Disorder, I was also court ordered to work with the community treatments in that city.

My therapist given to me was in one city, and the day treatment was in another city. The day treatment was in the morning and consisted of being handed a piece of paper on a topic, such as anger, the reading it as a group. I was the youngest person, 18, while the majority of the people were in their 40's so I felt quite intimidated by those "older" folks and a little scared of them. Because everyone was so much older than me, the staff tended to treat me as a functioning 40-year-old adult, which I was not. I wasn't even a functioning 18-year-old! So I felt very inadequate and it helped to lower my already low self-esteem.

The adult day treatment I had wasn't personalized or individualized to my need. It was the exact same for everyone, so I ended up feeling more like a number than an actual individual. I left the adult treatment team and went down to Columbus for a hospital that specialized in anorexia. Because my doctor and therapist were consistent, for 3 years, I was able to allow the abuse to come to the surface. But because I did not have the insurance, I could only stay in that hospital for 1 month, but I really needed long term treatment, at least 1 year if not 2 years. So what ended up happening was I kept the same doctor and therapist, but every 2 months I was hospitalized in one of the public hospitals for either anorexia or suicide attempts.

Eventually it got to the point where none of the hospitals in Columbus would take me, so I was sent up to Cleveland to be hospitalized instead of going to the state institution again. Eventually, 3 years later, the hospital said that my doctor could no longer see me because of my outstanding bill. I ended up in one of the public hospitals because of the problem of separating from my doctor and because I couldn't find a treatment team that would take me then. I'd have to be on a year waiting list and I needed someone then. The doctor at that hospital, unknown to me, recommended me for the Transitional Treatment Team at North Central Mental Health Services. I was able to get on it very quickly.

My needs when I started with the team were a psychiatrist, medication and access to help. When I first started the team my family and I and the case manager all got together and talked. Everyone got a chance to express their expectations and concerns. It also gave my parents a chance to meet who I'd be working with. Because my parents live 3 hours away from me, the team had little contact with my parents, but always called them if something critical came up and kept them informed. I was given a psychiatrist who took me off all my medications to see what medications I really did need or used as a crutch. I have an addiction to RX drugs and I like medications so I wasn't too happy with that, but I think in the end he made a good choice to do that. I was put back on medication, but 10 months later I was taken off all my medication because I could function without it.

The treatment team has 24 hour access help for me. During the day I could stop in the office and see whoever was on call that day. Because the team shared all information about that day. Because the team shared all information about what was going on with me, I knew whoever I talked to would know something about what was going on at that time. I also met and worked with each member so I was comfortable talking to them.

If it was night time and I was having a very hard time or I wanted to take pills or cut, I could call Emergency Services who would either call the on-call member so I was comfortable talking to them. If it was night time and I was having a very hard time or I wanted to take pills or cut, I could call EMERGENCY SERVICES who would either call the on call member of the team who would call me back and I could work it out with them or they'd cab me to North Central and I would see the clinician there. I felt more secure because I knew someone was always there.

I also learned that I didn't have to create a "crisis" to receive help or attention from the team, and a sense of stability was there because this help was concrete. All members encouraged me to use EMERGENCY SERVICES and to use the members of the team instead of waiting until it became a crisis or I created a crisis to let them know "Hey, I'm hurting, I need help." Through this I learned that I could work through most of my problems with someone else's help that it did not have to be a big mess to get the help, even for the "little" daily problem. I learned that I could rely on myself and I didn't have to run to the team for every little problem.

At the beginning I needed somebody around me, I lived by myself and had no friends in Columbus, and I needed someone to help me get through some nights. The team enlisted the services of the home based team who'd come once a week in the evening and it would give me a chance to get out of the apartment, and have someone around in the evening hours which were really hard for me because of the abuse. It helped me to feel safer. I quickly learned that the team had experience with adolescents. And it was a relief to have what was expected of me, be related to my age. They knew of and had understanding of the problems of adolescents and early adults. Because they were in touch with that, it made communication more open between us. This in turn helped me gain trust in them and helped alleviate any miscommunication between us that would cause problems. I was able to be more honest with them because they had an idea, and understanding of how a young adult's mind functions and that allowed me to feel safe enough to communicate honestly with them.

After these basic needs were met we started to work on some other problem areas in my life, such as socialization skills, emancipation skills and locating resources to best meet my needs. I had a fear of people. I believed that every person was out to get me, to harm me or hurt me in some way. I never had a lot of friends and I didn't make friends very easily, so we started with some of the co-consumers. I met two different co-consumers to see if either one would be a possible match. Sometimes I'd go over to the other's apartment or the mall, or to the movies. Even if we didn't hit it off, it was nice that the co-consumer was about my age and also had some sort of problem like myself so it didn't make me feel different than everyone else. At the Christmas party, I had a chance to meet all of the co-consumers in a real relaxed non-threatening atmosphere. What was also nice about the Christmas party, was that it gave us a chance to be with all of the members of the team in a friendly, fun way, and it gave us all a chance to put our problems and the work behind us and enjoy each other's company.

Although I had lived by myself, my parents handled all my money and my bills. So I didn't know the basic financial skills. The team helped me work out a budget for my living expenses and food. Just how to accomplish this task helped me to feel more independent and self-assured. I also feel I became more "adult-like" because of the added responsibility. And the team fully supported me taking over my finances and I knew they would help me with it when that was accomplished. I learned that I could be a responsible person and that I could handle money.

The Transitional Team also had access to resources that I did not have access to. They knew how to access the government's food stamp system, I did not. I usually ended up in tears when trying to work with the government because I can never get any answers out of them! When I looked at

moving to another apartment, the team had a housing specialist who would help me, the team also had a vocational specialist who helped me with schooling when it was time. The team knew of support groups in the community that I did not know how to locate. Therefore, they were able to individualize my treatment to meet my individual needs. Because it was individualized, it made me feel important to them and that I was an actual person and not a number.

When these needs were met, we went onto a new set. We wanted to work on moving me to a location closer to the agency with access to the bus line, which I didn't have before unless I did a 1/2 mile walk. We also wanted to further my socializing skills and find a way to get me out into the community and out of myself. I was terrified at the thought of moving to another apartment and I didn't know how I'd find one in another area of town on foot. Lucky for me, the team had a housing specialist who helped me locate a new apartment. The housing specialist or my case manager would take me to visit possible apartments within my budget. My case manager and I did a lot of talking to process the whole idea of moving and a change. I do not like changes. When I had found an apartment, the team contracted a moving team to move me, which not only helped me, but also my parents who live far away.

After the move, I was so glad to have my case manager because I'd call the team in an absolute panic and I needed someone to talk to, someone to reassure me that I was okay, that I was safe. In the end I found out that I could do major changes and survive them and it's okay to need reassuring and the need to feel safe. We talked about what I could do to help myself feel safe and it's okay to sleep with the light on and with a doll. I really believe that the move boosted my self confidence in myself because I proved to myself that I could do this and survive a major change.

My case manager came up with this idea of me volunteering because it would get me out into the community. I wasn't that big on the idea and wasn't sure I wanted to do it. Well, I ended up volunteering at not only one but two different hospitals and loving it. I found that volunteering not only pushed me out into the community, but also pushed me out of myself. I became less absorbed with myself and started to feel for other people and to have empathy for them. I also discovered that I had to pretend to be happy and that allowed me to act the feeling. And I found that by the end of the day, sometimes the smile was actually real and I could feel a tinge of happiness.

Finally, the time came that I wanted to go back to school and that I needed a therapy group for sexual abuse. I wanted to go to school, but I didn't have the money to finance the education and I was a little nervous about going back to school because I had been out of college for four years. The vocational specialist had a connection with the Bureau of Vocational Rehabilitation, who in the end, were able to help me finance my education. I started off in Radiology at a community college. I love medicine, but it just didn't feel right in my gut. My vocational specialist went to school with me to talk to the Learning Disabilities department at school to see how they could aide me and I found out what was available to me. I was glad to have the team to talk to and to help process this major change for me. School was another way to broaden my socialization skills and to help get me back into society, but I still needed not only the support, but also the direction of the team, like being given an assessment such as finding out what there is that I could join at school.

I still had my really bad days, when the problems of that day and of my past just got to be too much and I ended up in tears. It was really reassuring to know that I could call the team and someone would be there to help me process that day or to help me talk to a teacher about re-taking an exam on a day that I was not functioning. When I started to think about changing not only majors but schools, my case manager and I would weigh the pro's and con's at such a change. In the end, it was my decision, but by having her help me process this change I felt supported and more confident in my ability to choose what is right for me. When I made the change, from medicine to art, my case manager went to the school and talked to the staff about what was available to me, my schedule and work load and her concerns about school and me. This allowed not only open communication between school and myself, but also between my case manager and the school. So the transition was a smooth transition which helped me adjust to the changes.

Finally I had a goal to join a therapy group. By this time, I was ready, but not too sure about it. The treatment team researched and found a therapy group in the community for me.

At last I transitioned to the adult team. I cried and I was scared but I was allowed to express those feelings and they were acknowledged. Before the transition, my case manager and I worked through the process, talked a lot about it and she had to reassure me that everything will be okay. We also went to lunch with the new case manager and I had a chance to meet her and get to know her in a non-threatening environment and activity. My case manager shared with the new case manager my treatment and history and how best to help me help myself and what my needs were. In the end, although a little rocky at first, the transition went through fairly smoothly. I was ready and had been prepared for it by the team. It was the goal from the beginning to transition me into the adult mental health team.

I'm grateful for the Transitional Team because I was falling through the cracks of the system, they recognized this and were instrumental in guiding me down a road of recovery. With the help of the Transitional Team I learned how to help myself. I learned that I need to tell myself and that I'm okay and a good person. The team helped me to adjust to society and to fit back into the society I had left years ago. I found other ways to receive help and that someone would listen to me, that I don't need to cut myself to get rid of the pain, that they would help me walk through the bad times. They helped me gain confidence in myself by pushing me beyond my expectations but not theirs and by honestly believing and having faith in me. I learned I had choices that I could do what they suggested or not, either way it was my choice. I chose to suffer the consequences if there were any. It made me think and take responsibility for my own actions. I couldn't blame my actions on anyone else.

Today I am a sophomore at an art school and on the president's list, and I still volunteer at two different community hospitals. Last year I was the recipient of the Franklin County "Extraordinary Mile" award for the Consumer of the Year. I have worked very hard to achieve these milestones, but I know it wouldn't have been possible without the help, support, and care of the Transitional Team at North Central. I want to express my thanks and appreciation for them helping me grow and mature and become a valuable member of society. I would encourage any community without a transitional team to research the benefits and find an opportunity to incorporate these services in their community.

This paper was presented by Daniel Bridgeo, M.S., and Michelle Antholine at the Third National Case Management Conference; Winds of Change, October, 1994, Oakbrook, IL, and at the Workshop on Adolescence sponsored by the National Resource Center on Homelessness and Mental Illness, April, 1995, Washington, D.C.



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